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THE UNIVERSITY OF ALBERTA

AN ETHNOGRAPHY OF THE SPINAL CORD INJURY UNIT

by

Sharon Mary Ann Laskiwski

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND

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Date: October 10th, 1989

Dedication

This thesis is dedicated to my parents whom I love very much. To my mother, Olga, who inspired and stimulated me with her intellectual ability and creativity to further my knowledge in nursing and to my father, Emil, for his kind and generous ways and his compassion for people.

ABSTRACT

The purpose of this study was to examine the experience of being a spinal cord injury (SCI) patient in a rehabilitation institution. Qualitative techniques were used in this study as the patient's subjective knowledge and understanding of the experience was the information sought. Data were collected over three months using ethnographic methods of participant observation, field notes, unstructured interviews, and a personal diary for recording subjective impressions. Eighty hours of participant observation and interviews with 16 patients, 14 staff members, 8 family members, and 6 friends of the SCI patients were conducted on the unit, for a total of 51 interviews. Two to three tape-recorded interviews were conducted with most of the participants, and all interviews were transcribed. Common categories were established and used to organize the data, and the developing theory was repeatedly verified with the participants. A variety of measures including theoretical sampling were used by the researcher to enhance the reliability and validity of the study.

The findings of this study that identified the features of the SCI unit, the SCI patients' management of their bowel and bladder, and the concept of "killing time" during the patients' free time provide the groundwork for the SCI patient's response to illness and disability while in a rehabilitation institution. This included a description of ambulance attendants' contribution to the patients' recall of their accident, the use of medications during the acute phase of rehabilitation, wearing equipment that affected SCI patients' body image, the use of swearing as a coping strategy to build facades, and the changing nature of hope.

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I. INTRODUCTION

Statement Of The Problem

Patients are the central component of nursing practice (Robertson & Boyle, 1984, p. 48). It is the philosophy of nursing services to provide the best possible care to assist individuals to meet their physical, as well as, their emotional needs. Rehabilitative aspects of nursing care emphasize patients' achieving their full potential, and strives to protect and maintain their future health. Knowledge about the behavioral consequences of spinal cord injury (SCI) patients is incomplete (Bedbrook, 1985; Capildeo & Maxwell, 1984; Guttmann, 1976; Holt, Matthews, & Carlson, 1987; Peroin-Dixon, 1988; Urey, Viar, & Henggeler, 1987; Warms, 1987; Waters, 1987). In order to maximize the delivery of optimal nursing care to patients who have sustained a SCI, there is a need to understand, from the patient's perspective, what it is like to encounter permanent damage to the spinal column, and the thoughts and feelings one experiences during the rehabilitation process (Boyle, 1985; Douglas, 1976; Rosenthal, Marshall, Macpherson, & French, 1980; Trieschmann, 1980). Although SCI patients often have lengthy stays on a rehabilitation hospital unit, little has been documented about the patients' experience (Boyink & Strawn, 1981; Seidel, 1982). It is important for nursing to develop a knowledge base from which we can provide effective and holistic patient care. Information on patients' perspective regarding their thoughts, feelings, and behavior during hospitalization could add to the body of nursing knowledge. This information could be obtained from the patients themselves by eliciting what their experience means to them.

With increased survival rates of individuals with spinal cord injuries, attention has turned to the rehabilitation of SCI patients. Despite the research literature in this area, the patient's experience following a SCI is not understood. To date, researchers

have focused on specific aspects of rehabilitation, such as, the incidence of stress and the physiological and psychological risks associated with this crisis situation. Unfortunately, the importance of the patient's own perceptions of his or her recovery following a SCI has not been discussed in the literature.

Purpose And Rationale

The purpose of this study was to develop an understanding of what it is like to be a SCI patient and use this knowledge to improve the methods of nursing practice when caring for SCI patients going through the process of rehabilitation during hospitalization.

The incidence of spine injuries related to automobile accidents has been the focus of National and Regional studies (Adelstein & Watson, 1983, p. 65), and the National Center for Statistics and Analysis estimated that 6,000-10,000 auto accident victims die annually as a result of a broken neck (National Spinal Cord Injury Data Research Center, 1978). At present, significant gaps exist in nursing knowledge concerning the planning and implementation of nursing care to SCI patients (Stryker, 1977, p. 11). Warms (1987) and Waters (1987) noted that one such gap was whether or not health care is meeting the needs of SCI patients. Neither is it known if rehabilitative nursing care facilitates or impedes the client's ability to be integrated back into the community. This study provided information that addressed these issues, as well as, nursing concerns specifically related to caring for SCI patients during the rehabilitation phase of recovery. Inductive development of scientific theory in this area was initiated so that nursing knowledge could be based on facts rather than beliefs. A qualitative research approach was used to identify common themes and variables of interest from the perspective of the subjects. From this understanding, theories to conceptualize and explain the SCI patient experience were generated. Diers (1979)

noted the importance of preceding quantitative research with qualitative theory development.

The Research Question

The original question that guided this research was: "What is the experience of being a SCI patient on a rehabilitation hospital unit ?" Subquestions addressed in the study included:

1. What is it like to anticipate living with a permanent disability?
2. What factors influence a patient's response to living with permanent damage to the spine which has rendered the person quadriplegic or paraplegic (i.e., family members, significant others)?

II. REVIEW OF THE LITERATURE

The adjustment problems of individuals who have sustained permanent damage to the spine have not been addressed extensively in the research on spinal cord injuries. The literature on people with spinal cord damage was divided into four categories. The key concept for the first group of studies which addressed patient responses to a spinal cord injury was described as grief. The second group of studies focused on the affected individual assuming the patient role, and described aspects of social behavior associated with the role of being a patient. The third group of studies examined the effects of the cultural entity of a hospital setting on overall patient functioning. The fourth group of studies concentrated on coping with a permanent physical disability for SCI patients.

Grief

Human grief has been described and explored in religious writings, in fiction and non-fiction, and in social science and psychiatric journals (Comarr & Vigue, 1978; Kubler-Ross, 1975; Norris, 1978; Worden, 1982). Researchers who studied the grieving process indicated that grief involved a sequence of individual, subjective experiences. Some researchers described the behavioral, psychological, and somatic consequences that result from loss (Bowlby, 1973; Carlson, 1978; Kubler-Ross, 1971; Worden, 1982). Most of the findings on grief were largely exploratory, descriptive accounts of the researcher's personal experience in the field (Bartol, 1978; Cook, 1976; Nagler, 1950; Stryker, 1977; Wing, 1977); however, some researchers used measurement tools (Bourestom & Howard, 1965; Fordyce, 1964) and structured interviews (Nagler, 1950) to gather the data. Unfortunately, no attempt has been made to uncover SCI patients' own perception of the grieving process.

The experience of permanent spinal column damage was described by researchers as a traumatic, usually unanticipated event that had profound consequences for the survivor and involved physical and emotional aspects which frequently led to behavioral, psychosomatic, and/or emotional manifestations (Bartol, 1978; Bourestom & Howard, 1965; Cook, 1976; Fordyce, 1964; Nagler, 1950; Stryker, 1977; Wing, 1977). Some researchers suggested that these behavioral disorders were influenced by a lack of social support (Bartol, 1978; Bourestom & Howard, 1965; Fordyce, 1964; Wing, 1977), the individual's previous premorbid personality, and past coping mechanisms (Bourestom & Howard, 1965; Cook, 1976; Fordyce, 1964; Nagler, 1950; Stryker, 1977).

Researchers who studied grief concentrated on the permanent body losses that resulted in the initiation of the bereavement process. The general agreement among researchers who studied the grieving process was that most SCI patients develop physical, emotional, and social problems in response to their bereavement.

Patient Role

Although studies on patient role, in general, differ in style and sophistication, researchers who investigated the role of a patient commonly dealt with three major areas: the social aspect of sick-role expectations, the negative consequences of expected patient behavior during recovery, and the isolation of the patients from family, friends, and reference groups during rehabilitation. Generally, researchers who addressed the patient role described the patient's attitudinal and normative responses to this role. Unfortunately, these researchers have not addressed the specific responses of SCI patients and the ramifications of a SCI.

The most common data collection techniques used by researchers who studied the patient role were semi-structured questionnaires and interviews (Mauksh, 1962; Tagliacozzo & Mauksh, 1972), historical accounts (Brown, 1964; Cartwright, 1964;

Duff & Hollingshead, 1968; Goffman, 1961; Horsley, 1982; Parsons, 1951; Robinson, 1978; Shore, 1979), and case studies (Ciancutti, 1984; Field, 1967; Horsley, 1982; Rosengren & Lefton, 1969; Skipper, Jr., 1965). Two researchers used an emic perspective, that is, the patient's own view to determine their full meaning of the hospital experience (Mauksh, 1962; Tagliacozzo & Mauksh, 1972). Both of these studies were conducted in 1958 and 1962 respectively, and were thus considered dated at this point in time. Researchers who used the etic perspective, that is, the observer's views of the situation, were well represented (Brown, 1964; Cartwright, 1964; Ciancutti, 1984; Dorroh, 1974; Duff & Hollingshead, 1968; Field, 1967; Goffman, 1961; Horsley, 1982; Parsons, 1951; Robinson, 1978; Rosengren & Lefton, 1969; Shore, 1979; Skipper, Jr., 1965). Regardless of the research orientation, researchers who studied the patient role indicated that there were adjustment problems associated with this role (Duff & Hollingshead, 1968; Field, 1967; Mauksh, 1962; Robinson, 1978; Shore, 1979; Tagliacozzo & Mauksh, 1972).

Some researchers differentiated between the "sick role" and the "patient role" (Brown, 1964; Robinson, 1978; Tagliacozzo & Mauksh, 1972). For these researchers, the sick role occurred when a person was incapacitated by illness, and the patient role occurred when this same individual sought and accepted treatment from a health care facility (Robinson, 1978; Shore, 1979). Dorroh (1974, p. 25) suggested that the patient role may not be related to the sick role, whereas, Robinson (1978, pp. 48-58) felt that in order to understand patient behavior it was important to understand the sick role.

The Parsonian model of illness was a pervasive theme often found in the literature on the sick role. Researchers who studied the sick role and addressed the Parsonian model of illness described four main characteristics of the sick person: the sick person was exempt from certain normal social responsibilities, was not expected to take care of themselves or get rid of their illness by "will power," was motivated to get

well, and co-operated with medical experts (Brown, 1964; Mauksh, 1962; Parsons, 1951; Robinson, 1978).

Although, the social position of a patient involved particular rights and duties (Brown, 1964; Mauksh, 1962; Parsons, 1951; Robinson, 1978; Rosengren & Lefton, 1969; Tagliacozzo & Mauksh, 1972), there was no evidence of any particular model or conceptual design for discovering and documenting these rights and duties. One patient right frequently discussed by researchers who studied the patient role was that patients should have direct involvement with the decisions made about their care (Brown, 1964; Horsley, 1982; Shore, 1979; Skipper, Jr., 1965); however, little has been done to establish alternatives for partnership in health care.

While the characteristics and circumstances of patient behavior varied, associated with the patient role, there were some common features. Two of the most prevalent emotions experienced by patients were fear and anxiety (Dorroh, 1974; Field, 1967; Urey, Viar & Henggeler, 1987). Unfortunately, the tentative explanations for these feelings made by researchers who studied the patient role precluded definitive conclusions. For example, two researchers noted that the hospital and its equipment were, in themselves, anxiety producing (Ciancutti, 1984; Field, 1967). Tagliacozzo and Mauksh (1972) and Ciancutti (1984) suggested that not knowing what lies ahead of you created fears about treatments or regimes in health care settings. In contrast, both Dorroh (1974) and Field (1967) stressed that having no solid explanations of when, where, and why things happen on hospital units contributed to the creation of anxiety producing events. Nonetheless, many of the researchers who studied the patient role recognized that negative feelings prevail. Unfortunately, the extent to which the feelings of anxiety, fear, anger, guilt, hopelessness, and others impact on the patient's ability to recover and the degree to which the patient role causes adjustment problems for SCI patients were largely unknown.

Researchers who studied the patient role cautioned against over-generalizing study results obtained from these investigations because the thoughts and feelings one experiences in this role were largely unknown (Parsons, 1951; Rosengren & Lefton, 1969; Tagliacozzo & Mauksh, 1972). The generalizability of studies on patient role was further hampered by the variety of research methods used to infer the extent of patient satisfaction while receiving health care. Furthermore, in the majority of these studies, assessment of patient adjustment, more specifically those individuals who required lengthy stays in hospital settings due to chronic health conditions, such as, congestive heart failure, renal failure, chronic obstructive pulmonary disease, and spine injuries was based primarily on observer reports. In-depth individualized investigation of "permanent" spine injured patients' response to receiving health care was lacking.

Despite the concerns about methodology and generalizability, the results of the patient role studies provided a valuable direction for this study. These studies offered evidence that SCI patients, who usually require long-term health care, were at risk for future adjustment problems and, therefore, need preventative nursing care.

The Cultural Entity Of A Hospital

Researchers who studied patients' responses to institutionalization examined the customs, language and communication system of hospitals. A number of researchers stated that the uniqueness of hospital settings warranted investigation into the social grouping of individuals in health care facilities (Brink & Saunders, 1976; Brown, 1964; Ciancutti, 1984; Germain, 1979; Mauksh, 1962; Mead, 1976; Spector, 1985; Tagliacozzo & Mauksh, 1972). The main conclusions from researchers who studied the cultural entity of a hospital were similar to researchers who examined the patient role. For example, Brink and Saunders (1976) and Brown (1964), concluded that learning, motivation, and evaluation (all psychological variables) for patients constituted necessary and sufficient conditions for the maintenance of the hospital social system.

Focusing more specifically on hospital units, Germain (1979) examined a cancer unit and determined that individual units within the hospital were subcultures, encompassing particular role behaviors. Unfortunately, research dealing with the specific cultural entity of a rehabilitation hospital unit for SCI patients was non-existent.

A few researchers who studied hospital settings identified several rituals or cultural norms of hospitalization, such as, the wearing of hospital-issued clothing, having vital signs taken, and being assigned to a particular room (Brink & Saunders, 1976; Mauksh, 1962). These researchers suggested that rituals helped the patient conform, while at the same time, they also reduced the person's individuality and power. To further support the notion that hospital rituals reduced a patient's individuality, Tagliacozzo and Mauksh (1972) suggested that patients frequently were not familiar with the particular norms of hospital settings and thus added to the power of those who worked, and were intimately familiar with the rules and privileges granted to expected role behaviors within these settings.

Also, the literature on hospital culture dealt with subjective perceptions. Mauksh (1962) noted that the trend in modern hospitals of having single or double rooms decreased the patient's ability to become familiar with the hospital community as the individuals who could explain it, that is, other patients were often not available to each other. This finding supported Ciancutti's (1984) theory that patients demonstrated varying responses to receiving health care and that these responses depended upon their previous experiences of hospitalization and the extent to which they were informed by others about the normative behaviors expected within the culture.

Researchers investigating the cultural entity of a hospital setting usually discussed the unfamiliarity of the surroundings and the apprehension or anxiety it tended to create in patients. Generally, these studies explored and described what it was like to be a patient on a hospital unit, from the observer's point of view, and little was known

about the perspective of the subjects themselves. Studies on cultural characteristics of a hospital unit described the influence of normative behaviors on the patient's potential for successfully completing a rehabilitation program; unfortunately, little has been documented on the cultural entity of a rehabilitation hospital from the perspective of SCI patients.

Coping

The studies on "coping" stressed the positive aspects of adaptation for SCI patients. Although several factors contributing to the successful recovery and reintegration of the patients back into the mainstream of society were identified by researchers who studied coping, the predominant influences were on-going rehabilitation and the presence of support groups (Bartol, 1978; Bedbrook, 1985; Capildeo & Maxwell, 1984; Cook, 1976; Fordyce, 1964; Holt, Matthews & Carlson, 1987; Kubler-Ross, 1968; Nagler, 1950; Seidel, 1982; Shore, 1979; Warms, 1987; Wing, 1977). Even though two factors were typical, Bedbook (1985) and Seidel (1982) cautioned against using a generalized criterion for the rehabilitation of SCI patients and suggested that each affected person required an individualized program. These researchers pointed out that personalized health care during long-term institutionalized rehabilitation facilitated the mobilization of effective coping mechanisms for patients and enhanced their chances for positive adaptation.

Considering the magnitude of the physical, psychological, and social changes experienced by SCI patients, researchers who studied coping agreed that most SCI patients have the potential for experiencing problems coping with adjustments. For example, Boyink and Strawn (1981) noted that the physical consequences of sustaining damage to the spine (due to accident or disease) included paralysis to the limbs, bowel, bladder, and reproductive organs, depending upon the level of injury to the spine. Given the physical devastation experienced by SCI patients, it was not surprising that

the concept of self and alterations in body image were the primary themes identified by researchers who studied coping in relation to patients' psychological adjustments to long-term disability (Norris, 1978; Wing, 1977).

Also, the literature on coping dealt with specific life style modifications SCI patients experienced. According to Bartol (1978) and Cook (1976), the manner in which spine injured patients carried out employment or leisure activities required modifications, such as, some patients made arrangements to work in their home and they participated in sports events if the buildings that housed these events were wheelchair accessible. Despite the research on coping, SCI patients were a risk group who still required information on the nature and typical course of their injury and on the strategies necessary to benefit from the health care they received (Bartol, 1978; Bedbrook, 1985; Fordyce, 1964; Guttmann, 1976; Holt, Matthews & Carlson, 1987; Nagler, 1950; Stryker, 1977).

While the literature orientation on coping focused on adaptation of SCI patients, no research specifically addressed effective coping strategies that were experienced by the patients. Trieschmann (1980) and Brown (1961) suggested this information would be a valuable contribution to the already existing body of knowledge on coping. Despite the conclusion in the literature that SCI patients were at special risk for maladjustment problems, most of the researchers who studied coping did not deal directly with patients (Bourestom & Howard, 1965; Fordyce, 1964).

Overall, the literature on coping emphasized findings of practical importance to SCI patients, family members, and health-care professionals in an attempt to devise beneficial means to deal with chronic illness or disability. To date, little research has been geared to the specifics of what it is like to be a SCI patient; therefore, insufficient background information existed to warrant an intensive investigation of effective coping strategies for this particular target popluation. Hopefully, the groundwork established

by this study can be used by future researchers investigating the complex phenomenon of coping.

Summary

The literature on patient's response to chronic illness or disability after sustaining permanent damage to the spinal column provided a useful direction for this study. The lack of definitive findings was due to several factors, including the power of *a priori* assumptions (such as patient grief or coping assumptions) to influence study results. Little verified information relevant to the adjustment of long-term rehabilitation hospitalized SCI patients existed; therefore, this study was devised as a beginning, factor-searching investigation of the phenomenon. In order to avoid biasing the study results through *a priori* assumptions about the situation, this study was designed to investigate the SCI experience from the perspective of the subjects themselves. It is hoped that by doing so this study will provide a more valid foundation for future studies in the area.

III. METHODS

The purpose of this study was to examine the experience of being a SCI patient in a rehabilitation institution. It is generally agreed that the choice of method chosen in a research investigation should be determined by the research question, the purpose of the study, how much is already known about the topic, the maturity of the concept, and the constraints of the subjects or setting (Bogdan & Biklen, 1982; Ellis, 1982; Field & Morse, 1985; Knafl & Howard, 1984; Mead, 1976; Mishler, 1979; Morse, 1985; Reichardt & Cook, 1979). As the experiences of SCI patients have not been comprehensively and systematically investigated, a research design suitable for a first level research question was selected (Diers, 1979). Studies that focused on the first level of theory development were "descriptive in nature and occur at the exploratory or formative stage of theory development" (Field & Morse, 1985, p. 9). As this study was a first level investigation, a qualitative method was chosen, and this chapter discusses the ethnographic approach, sample characteristics, data collection and analysis, issues of reliability and validity and, finally, ethical considerations involved in this study.

Qualitative Methods

As qualitative research is an inductive approach used to develop understanding and knowledge from the emic perspective, that is, knowledge is derived from the subject's view of the experience (Aamodt, 1982; Davis, 1986; Field & Morse, 1985; Kay, 1982), it was considered the appropriate method for use in this study. Qualitative research is usually conducted in the natural setting as the context in which the phenomenon occurs is considered to be part of the phenomenon itself (Field & Morse, 1985; Mead, 1976; Mishler, 1979). A qualitative approach is a mode of inquiry which is "concerned with understanding human beings and the nature of their transactions

with themselves and with their surroundings" (Benoliel, 1984, p. 3). Using a qualitative approach provided a means by which the experience of SCI patients in a rehabilitation institution could be investigated. Theory that is developed by utilizing qualitative methods relates to the world from which it arises; whereas, the relevance of research that utilizes deductive approaches varies widely.

To date, research studies concerned with the experience of SCI patients have used deductive methods of inquiry and, to a large extent, have omitted these individuals' perceptions of sustaining permanent damage to the spinal column and their day-to-day situations. This has resulted in a fragmented understanding of their predicament. A qualitative method, which included an inductive approach, enabled this researcher to gain a fresh perspective, in an area where little is known, about the experiences of SCI patients. Also, this researcher was able to obtain first hand information from patients who were involved in a rehabilitation program and were going through the SCI experience.

In order to evaluate and expand nursing practice, it is important for the nursing profession to conduct research to generate theory. Nursing research improves our understanding of the experience, enhances our nursing judgement, and ultimately improves our nursing care (Bogdan & Biklen, 1982; Diers, 1979; Field, 1967; Leininger, 1985). As a research approach, a qualitative method was well suited to the purpose of investigating the experience of being a SCI patient from the patient's perspective.

Ethnography

The particular qualitative approach used in this study was ethnography, which is defined as "a generalized approach to developing concepts to understand human behaviors from an emic point of view" (Field & Morse, 1985, p. 21). Ethnography is a method of systematic collection, description, and analysis of data used to develop

concepts for understanding human behaviors (Aamodt, 1982; Davis, 1986; Field, 1983). This particular qualitative approach fits into the category of research called "factor-searching" that is concerned with the context of discovery and leads to extensive narrative description of cultural themes and patterns (Aamodt, 1982; Robertson & Boyle, 1984). Also, ethnography attempts to learn what knowledge people use to interpret experience and mold their behavior within the context of their culturally constituted environment. The use of such a method allows for the flexibility that is required in an exploratory study. Accordingly, ethnography offers a systematic means for developing an understanding of individuals who sustained permanent damage to their spine, and it makes use of "self" as a participant observer who gathers data through both informal interviewing and on-site participation (Morse, 1989, p. 62).

The ethnographic approach is guided by the presupposition that over time individuals' interpretations come to constitute a perspective, which is a combination of beliefs and behaviors that characterize their definition of a social world. Ethnography is based on the presupposition that some groups of people share a specific social, psychological, and cultural problem that is not necessarily articulated. As a research approach, an ethnography is well suited to the purpose of investigating the experience of being a SCI patient from the patient's perspective. The result of using an ethnographic approach permitted this researcher to describe the experience of SCI patients and accounts for the cultural variation among the subjects that participated in this study. In addition, the usefulness of the final report of an ethnography study, for the practice of nursing, provides a guide for recognizing and evaluating the needs of individuals and groups of individuals, and offers recommendations of future strategies for enhancing the quality of a human experience.

Sample

This study had 162 participants and included: 34 patients, 96 staff members, 17 family members, 12 friends of SCI patients, and 3 individuals who visited the unit because of their association with SCI interest groups. Subjects were selected based upon their ability and receptivity to provide rich enough data to allow the researcher to discover the cultural ideology that surrounded the experience of SCI patients, and the sample size was determined when no new information was obtained.

The interviewed sample consisted of 16 SCI patients (13 males and 3 females), 14 staff members (including individuals from the Nursing, Medicine, Psychology, Occupational and Physio Therapy, Housekeeping, Audio Vision, Nutrition and Food Services, Maintenance, Therapeutic Recreation, Social Services, and Education Departments in the study area), 3 representatives from outreach organizations (The Canadian Paraplegic Association, Injury Awareness and Prevention Program, and The Rick Hansen Centre), 8 family members (3 mothers, 3 fathers, 1 uncle, and 1 aunt), and 6 friends of the SCI patients.

Sample Selection

For this study, SCI was defined as injury, disease, or surgery of the spinal cord that resulted in permanent paralysis of all four extremities and the trunk (quadriplegic) or permanent paralysis of both lower extremities (paraplegic), depending upon the level, severity, and extent of irreversible damage to the spine for the affected individual. Key informants who participated met the following subject criterion:

1. fit the definition of SCI provided in this study;
2. was 18 years old or over, based on chronological age from birth;
3. spoke and read fluent English;
4. gave informed consent to participate in this study;
5. was a patient on the rehabilitation unit;

6. was medically diagnosed as a quadriplegic or paraplegic; and
7. was willing to answer questions and provided information in an informal give-and-take situation.

In qualitative research, it is important to select key informants who have knowledge of more relevant information and are willing to participate (Morse, 1985, p. 4). It was the goal of this researcher to obtain rich data that was comprehensive, relevant, and detailed that resulted in voluminous notes. The selection of subjects was based on nonprobability, convenience, or opportunistic methods. Individuals were selected on their willingness to participate and their ability and willingness to share their experience with the researcher.

The biographical characteristics of the SCI patient sample consisted of eighteen patients who were quadriplegics and thirteen patients who were paraplegics (see Table 1). The ages of the SCI patients ranged from 17 to 67 years of age (with a mean of 33.8 years). Three patients were female, and the remaining patients were male. Ten patients were married, 15 patients were single, 1 patient was widowed, and five patients were divorced. While the patients occupations varied considerably, many of those in the sample were completing their high school education. Their length of stay on the unit was between 6 to 143 weeks (with a mean of 24.5 weeks).

Sample Size

The adequacy of sample size is assessed by the adequacy of the information obtained from the sample (Morse, 1985; Reichardt & Cook, 1979). Morse (1985) suggested that adequacy was attained and sampling and data collection could be stopped when "the theory is complete, does not have gaps, and has been confirmed" (p. 4). This study was not conducted with the intent of generalizing its findings to other situations. The purpose of this research was to develop a culturally specific understanding of SCI patients during their stay in a rehabilitation institution.

Table 1: *Biographical Characteristics of the Informants*

	Characteristics				
Informants	Age (years)	Sex	Marital Status *	Level of Education **	Length of Stay (weeks)
1.	67	F	M	Grade 6	6
2.	44	F	D	Grade 12	16
3.	24	F	M	Grade 10	17
4.	41	M	D	Grade 10	8
5.	60	M	D	Grade 8	6
6.	39	M	M	University	8
7.	21	M	S	Grade 12	6
8.	55	M	S	Grade 5	30
9.	30	M	S	Grade 9	10
10.	25	M	S	Grade 10	7
11.	56	M	M	none	20
12.	53	M	M	University	6
13.	33	M	D	University	12
14.	43	M	M	College	14
15.	19	M	S	Grade 12	10
16.	23	M	S	Grade 12	14
17.	28	M	S	Grade 12	8
18.	24	M	S	Grade 12	24
19.	28	M	S	Grade 12	24
20.	18	M	S	Grade 12	20
21.	41	M	M	University	7
22.	18	M	S	Grade 12	6
23.	30	M	M	Grade 12	43
24.	33	M	D	Grade 12	24
25.	17	M	S	Grade 11	22
26.	20	M	S	Grade 12	17
27.	17	M	S	Grade 10	143
28.	25	M	S	Grade 9	126
29.	25	M	M	College	6
30.	53	M	M	Grade 12	46
31.	38	M	W	Grade 9	52

Note: *Marital Status married-M
single-S
widowed-W
divorced-D

**Level of Education
Grade completed/college or university degree obtained.

Informants were observed and interviewed until the researcher obtained no new information and the data became sensibly consistent and free of gaps.

Data Collection

The researcher gained access to the study group, and data were collected over three months using the ethnographic methods of participant observation, field notes, and unstructured interviews. A personal diary for recording subjective impressions was also kept by the researcher. All the people on the SCI unit were considered potential subjects, including the staff and family members. Informants were selected on their willingness to share their experience with the researcher. Interviews with 16 patients, 14 staff members, 8 family members, and 6 friends of the SCI patients were conducted for a total of 51 interviews and 80 hours of participant observation.

Gaining Access to the Study Group

Gaining access to the study group was the first step in this study. The purpose of this initial step was to meet with prospective informants. This was accomplished by speaking with local people already familiar with potential subjects, by speaking with the physicians on the unit, and by attending a staff meeting to explain the study to the health team members. The staff were supportive and interested in the study and immediately gave verbal approval.

Gaining entry to the study group and establishing trust with the informants were important when doing qualitative research. Field and Morse (1985, p. 55) suggested that researchers spend a week in the study area to seek acceptance from the informants and to establish the research role prior to the commencement of formal data gathering. The week this researcher spent on the unit was beneficial for three reasons: it allowed the researcher to become familiar with the study area and served as an orientation, the informants became accustomed and more relaxed in the presence of the researcher, and the role of the researcher was established by "hanging around" the housekeeping staff

first, then the patients and nursing orderlies to gain the trust and confidence of everyone on the unit. During this period, the researcher became acquainted with the conversational patterns and normal behavior of the study group, the organization of their activity, the social interaction patterns, and identified who were the informal leaders.

Before commencing data collection, this researcher discussed, in private, the research topic in general terms with each prospective informant, and explained that tape recorded interviews approximately one hour in length were required. An informed consent was obtained by the researcher at this time from those key informants (i.e., SCI patients) and secondary informants (i.e., staff and family members, SCI patients) wishing to participate in this study (see Appendix A). A note was placed on the front of each chart to inform the health team members that this study was being conducted and that the patient had consented to participate (see Appendix B). Two patients refused to participate in this research. Both of these patients said that they were not interested in the study. If a SCI patient, staff or family member did not wish to participate, no data was collected from the non-participants. For example, if the researcher entered into a room and observed a non-participant patient interacting with participants, the researcher left the room.

Participant Observation

The level of participant observation used in this study was observer-as-participant, that is, the majority of the researcher's time was spent observing and interviewing, with no participation in the work role. The purpose of participant observation is to make observations of typical situations and to obtain accurate detailed descriptions of the setting (Field & Morse, 1985; Germain, 1979). Participant observation permitted the researcher to capture the process of interpretation in a manner that meets the stipulations of symbolic interaction, that is, catching the process of

interpretation by placing and immersing oneself in the social situation being investigated (Denzin, 1978). This method of participant observation involves social interaction between the researcher and the subjects, and it is important that the observer be aware of his or her selective process in deciding what to observe (Denzin, 1970; McCall & Simmons, 1969). The observations were recorded as field notes and were helpful in guiding subsequent observations and interviews. When interviewing SCI patients, the researcher was able to observe their day-to-day activities. For example, one SCI patient was observed to be wearing a plastic brace around the trunk of his body. This observation prompted the researcher to ask this patient the name of the brace, and he went on to explain the experience of wearing this piece of equipment. Observing SCI patients enabled the researcher to determine if the patients participated in their reported activities.

Field Notes

Field notes of the observations consisted of daily written notes. These were in the form of reconstructions of observations and conversations, and they were used to supplement the tape recorded interviews. The notes recorded in the setting were placed in a small notepad and were brief so that the researcher could capture as much detail during an interaction as possible. These notes were later transferred and expanded onto a personal computer system that same day to prevent loss of information and to ensure accurate recall of the events. The small notepad was easy to record in, was portable, and relatively unobtrusive to use. Data from the field notes were included in the data analysis.

Unstructured Interviews

Because the research questions dealt with an area where little verified information currently exists, the use of an unstructured interview technique was used (Diers, 1979; Field & Morse, 1985; Reichardt & Cook, 1979). Unstructured

interviews allowed the researcher to explore the subject's perspective of being a SCI patient, and the interviews were directed by the informant's responses. These interviews began with superficial, broad questions and increased in depth as categories and/or relationships were identified (Field, 1983; Field & Morse, 1985; Mead, 1976).

It was the intent of this researcher to take on a learner role as it is the informants who had the information that was being sought. One to three tape recorded interviews were held with each subject, and the interviews lasted from 30 to 90 minutes, depending on the receptivity of the informants, the amount of information they were willing to share, and their contribution to the emerging theory. Analysis of the first round of interviews, in conjunction with the data from secondary informants, resulted in the initial categories and provided direction for second and third round interviews.

Second and third round interviews were more structured, with an increased use of direct questions to validate and extend the understanding of the structure of the data. Using these techniques, analysis completed with the first round interviews was verified, gaps in areas of the interviews were filled in, cross-checking with informants was made possible, and the development of an emerging theory was facilitated. All of the unstructured interviews were tape recorded and subsequently transcribed.

The researcher obtained an audio recording of the subject's verbal consent each time they participated in the taped interviews, and informants were reminded to discuss information they volunteered for the study. Key informants were asked to discuss their own experience of living with a permanent spinal cord injury, and of being a patient situated in a rehabilitation hospital unit. In addition, secondary informants were asked to discuss their own experience of involvement with SCI patients. The length and depth of each interview were determined by the tolerance of the subject. Participants were eager to discuss their experiences, and they provided information about the

practices and beliefs surrounding a person with a SCI from the time of the incident to the time they were discharged from the unit.

In order to establish the support and trust of the informants, the researcher conducted the interviews on the unit in a quiet environment, a room that was free from interruptions while being receptive to each participant's current situation (Field & Morse, 1985). During the interviews, this researcher probed for additional information, made associations, and verified assumptions to gain the most understanding from the informants (Field & Morse, 1985; Germain, 1979). Data collection ceased when no new information, categories, or negative informants could be found (Field & Morse, 1985). Examples of questions used in this study were:

1. Tell me all about your experience of becoming a SCI from the very beginning.
2. What is it like to be a SCI patient?
3. What is your experience of being a SCI patient on a rehabilitation unit?
4. How has being admitted to a rehabilitation institution affected your life?
5. How do you feel about being a SCI?
6. Tell me more about _____.

Personal Diary

Subjective impressions and hunches by the researcher were kept in a personal diary. The personal diary was a useful means for keeping tract of the researcher's personal thoughts and feelings during the study. Also, insights about engaging in research activities were recorded daily in this diary and these notations assisted the researcher to plan the conduct of this study.

Data Analysis

The purpose of data analysis was to code the data so that categories may be recognized and analyzed, behaviors noted, and a data filing system developed that provided a flexible storage system for retrieving data (Field & Morse, 1985, p. 97). Data analysis for this study was conducted concurrently with data collection. The ethnographic approach stipulates sequential data collection in order to characterize a situation and provide an in-depth descriptive analysis of cultural phenomena (Robertson & Boyle, 1984; Spradley, 1980). Several strategies were incorporated in this study to enhance the achievement of this goal. Unstructured interviews were transcribed verbatim and checked for accuracy by reviewing the tape and transcript. The interviews and field notes were read, looking for significant incidents, patterns of behavior, isolated situations, and recurrent statements of the informants.

The initial content analysis and coding from the first round of interviews and observations involved the identification of open, substantive codes. Each example or each theme identified in the interviews and field notes was coded. In order to ensure attainment of a theoretical coverage, an attempt was made to use as many codes as possible at this stage of data analysis (Bogdan & Biklen, 1982; Brink & Saunders, 1976; Goodwin & Goodwin, 1984). As data within each of these categories were compared and contrasted, new categories emerged. The emerging categories were then compared to each other to ensure that they were mutually exclusive.

Throughout the process of data analysis, an attempt was made to explore and establish linkages. These linkages provided conceptual order for the developing categories. As more information was compiled on each topic, the major categories were sorted into smaller categories. Information obtained from secondary informants was compared to data collected from key informants to verify and extend analysis. The researcher developed hunches about relationships among behaviors, participants, and

activities within the data which permitted the development of tentative propositions about these relationships. Field and Morse (1985) suggested that tentative propositions could be used to guide data gathering; therefore, these propositions were used to guide further data collection in this study. During data analysis, discussions with the thesis committee members, professional colleagues, and classmates provoked further thinking about the analysis, and allowed for refinement of the linkages between the data. The exploration, testing, and revising of the linkages ceased when all the categories were placed into a conceptual framework.

The researcher also distinguished between representative cases and atypical (negative) cases. Representative cases were those informants who appeared with regularity and encompassed the range of behaviors described within a category. Atypical (negative) cases were those informants who appeared infrequently and depicted a small range of events which were atypical of the larger group. Negative cases are important as they help to clarify additional causal properties which influence the phenomena under study (Denzin, 1978). Data analysis continued with each subsequent interview and observation until no new information, categories, or negative informants could be found.

To establish a data filing system, the researcher employed a manual method using highlighting pens. The persistent words, phrases, and themes were coded in the right margin of the transcripts and field notes as to the broad category they belonged to. The use of spaced paragraphs and wide margins on each page allowed room for notation and coding procedures by the researcher. Each transcript and the field notes were photocopied, cut up, and categorized. Colored stripes identified each informant and each interview. All pages of the transcripts were numbered sequentially, with each page indicating the interview number and the informant's number. Significant passages were cut and taped onto a full size sheet of paper and filed into a folder that represented

each category. Field and Morse (1985, p. 102) noted that color coding was a fast method for identifying all data by allowing pieces coded for analysis to be traced quickly to the original source.

Reliability And Validity

The issues of reliability and validity are important to all types of research (Field & Morse, 1985; Goodwin & Goodwin, 1984). Every researcher has a responsibility to elicit and provide an accurate rendition of the phenomenon being investigated, taking into consideration those factors which enhance the credibility of the research. This section will address issues of reliability and validity that were relevant to the context of this study.

Two approaches to evaluating the reliability and validity of qualitative research are the general approach (i.e., Sandelowski, 1986) and the sampling approach (i.e., Morse, 1986). The general approach constitutes a number of issues, while in the sampling approach, accessing a representative study group is the central concern. Both of these approaches were important and relevant to this investigation.

The General Approach.

Reliability is concerned with the extent to which random variation in the study may influence the stability and consistency of the results (Denzin, 1970; Field & Morse, 1985; LeCompte & Goetz, 1982). Because subject selection, data collection, and data analysis are conducted in different ways and for different purposes than a quantitative study, it is generally agreed that a qualitative study will raise different questions concerning reliability and validity (Goodwin & Goodwin, 1984; Reichardt & Cook, 1979). Exact replication of qualitative studies is rarely achieved because of their emphasis on constantly changing, ever evolving natural phenomenon involving settings, subjective perception, and the fact that the researcher is the main study instrument (Giovanetti, 1981, p. 145). Nonetheless, there are means to markedly

enhance the reliability of each qualitative study. For example, LeCompte and Goetz (1982) suggested that to enhance the replication of a qualitative study special attention should be devoted by the researcher to clearly delineate the physical, social, and interpersonal contexts within which the data are collected. To enhance the reliability of this study, one of the strategies used by this researcher was detailed written field notes, reflecting both objective descriptions of the subjects, setting, and behaviors and subjective impressions, ideas, and hunches. The decision trail of this study is presented throughout this thesis and must stand to be evaluated by the reader.

Validity is concerned with the extent to which the research findings represent reality (Field & Morse, 1985, p. 139), and it includes two related components known as internal and external validity. Internal validity refers to the degree to which researchers are actually observing what they believe they are observing (LeCompte & Goetz, 1982, p. 40). Internal validity is considered to be a major strength of qualitative research (Aamodt, 1982, p. 209) because of its "grounding" in reality through the use of the inductive approach (Aamodt, 1982; Field & Morse, 1985; LeCompte & Goetz, 1982). The unstructured interview format allowed the researcher to explore the informant's perspective of the situation. Several measures were used in this study to ensure that reality-based theory development occurred (i.e., unstructured interviews and discussions with the committee members); however, the fieldwork part of the study may have suffered from the "going native" threat to validity, and it is for this reason that the data must be considered only in terms of their contribution to the findings.

External validity refers to theoretical generalizability (LeCompte & Goetz, 1982, p. 40). Generalizability is not the goal of qualitative research (Aamodt, 1982; Field & Morse, 1985; LeCompte & Goetz, 1982). As previously mentioned, qualitative studies cannot be replicated exactly (Field & Morse, 1985). It is agreed that the researcher's

purpose is to demonstrate the typicality of a phenomena observed at a given period in time (Aamodt, 1982; Field & Morse, 1985; LeCompte & Goetz, 1982; Morse, 1985). Accurately identifying common themes, ideas, and concepts from detailed observations in the form of field notes and transcripts, rechecking observations, clarifying informant's statements, and sharing interpreted data with the informants to determine that their view is not misrepresented were some of the methods this researcher used to enhance the durability of external validity in this study.

The more time the researcher spends with a group, the more opportunities for continual data analysis and comparison for refining the constructs so that a match between the categories developed by the researcher and the informant's reality is achieved (LeCompte & Goetz, 1982). The researcher was the sole interviewer in this study and was responsible for data analysis. This extensive involvement in the investigation enhanced the process; however, the relationships that developed between the researcher and the informants must be discussed because it undoubtedly affected the data collection. The description of this relationship is essential in order that validity of a study can be more adequately judged (Sandelowski, 1986).

Strategies that were incorporated into this study to minimize threats to credibility were founded on the researcher's attempt to verify the data by asking informants about the same content. For example, information obtained from one informant about what it was like to be in a wheelchair was verified by asking other SCI patients about this same experience. Frequent checks for representativeness of the data and coding categories were completed. Examples were used to explicate and present the data. To correct for bias or distortion and to confirm and validate interviews, data from secondary informants were used, and the researcher obtained validation from key informants through direct questioning to ensure that categories were meaningful and reflected SCI subjects' perceptions of their circumstances. Considerable effort was required on

behalf of this researcher to examine statements carefully so as to be certain that meanings were accurately portrayed. Further determination of the credibility of the findings in the study awaits the judgement of the reading audience.

The ability of any researcher to demonstrate credibility is critical to the value of the findings (Field & Morse, 1985). Issues of reliability and validity are essential criteria of the research design (Field & Morse, 1985; Knafl & Howard, 1984; LeCompte & Goetz, 1982; Sandelowski, 1986). Several methods have been incorporated (i.e., detailed field notes, rechecking observations and responses) to strengthen both the reliability and validity of this study. Careful use of the ethnographic technique by the researcher ensured that developing ideas, categories, concepts, and theories emerged from the data. Accessing knowledgeable secondary informants to gauge whether the developing theory was "reality-based" further enhanced the representativeness of this study. Finally, the researcher consulted with committee members and staff members on the research unit to verify that the conclusions were following in a logical progression. Whether this study meets the criteria, beyond the verification already discussed, will be determined once the findings are disseminated to the public and reaction is received.

The Sampling Approach

The use of appropriate sampling procedures is central to the establishment of reliable and valid findings in any research. The objective of data collection in this study was to obtain information that was comprehensive, pertinent, and detailed. To achieve this objective, the researcher chose a non-probability sample. The non-probability sample, in the form of purposive or theoretical sampling, was used to obtain informants who were deliberately selected according to the direction and theoretical needs of the study. Theoretical sampling is used to collect more data, to examine categories and linkages, and to ensure that the evolving theory is representative of the topic being

investigated (Diers, 1979; Morse, 1986). In this way, the use of theoretical sampling allowed the full range or variation of categories to emerge which were required to guide the emic perspective of theory development in this study.

Appropriateness and adequacy criteria have been suggested by Morse (1986) for evaluating sampling strategies in qualitative research. Morse (1986) defined appropriateness in terms of accessing data that is representative of the topic being investigated, and she defined adequacy in terms of the quality, completeness, and amount of information provided by the informants. Obtaining data from individuals who actually experience the phenomena under investigation, and considering that the informants voluntarily participated in this study, contributed to the likelihood of this researcher collecting the most representative and insightful data; thus, meeting the criteria of appropriateness. In this study, the categories were considered saturated when no new information was found, information was repetitive, and the researcher achieved a sense of coherence (Morse, 1989, p. 186). In addition, data analysis was verified with the original informants.

Ethical Considerations

Ethical clearance for this study was required by the Ethics Review Committee of both the University of Alberta Faculty of Nursing and the host institution. In order for patients and staff to know what it is like to have an observer on the unit, the researcher entered the setting as a guest for one week. Data were not collected during this time. At the end of this period, the researcher determined if the setting was suitable and consents were obtained from all patients, staff and family members wishing to participate in the study (see Appendix A). A note was placed on the front of each chart to inform staff members that this study was being conducted and that the patient had consented to participate (see Appendix B).

If the researcher had not obtained consent from the majority of persons located on the SCI unit, another setting would have been sought to achieve a representative sample. Some of the SCI patients were not able to sign their full name on the consent form due to a physical limitation of not being able to move their extremities; therefore, an "X" provided by subjects on the consent was considered acceptable by the researcher. The tape recorded verbal consents were obtained by having SCI patients read the consent form or by having the researcher read the consent form to these patients.

The researcher discussed the research topic in general terms, and explained with each prospective informant what participation involved (Douglas, 1976; Rosenthal, Marshall, Macpherson & French 1980). During data collection, the researcher explained to each informant that participation in this study was voluntary, and that they could withdraw from the study at any time. Ongoing verbal consent was obtained each time any informant was interviewed.

The recorded interviews, transcripts, field notes, and personal diary were kept by the researcher in a locked file. The identity of the informants on the transcriptions was coded to protect each subject's anonymity, not confidentiality, as words were typed verbatim in this final report. The personal identity of the informants was further protected through alteration of characteristics (see Table 1) and quotations in this thesis. The tapes of the original recorded interviews and transcriptions will be retained by the researcher for 5 years after the study is completed and kept in a secure place. After 5 years from the day that the study is completed, the researcher will destroy the tapes of the original recorded interviews. The transcriptions of the tape recorded interviews will be kept by the researcher for an indefinite period of time. Completion of the study was determined by the thesis committee members approving this report. The researcher may wish to use the transcriptions of the tape recorded interviews obtained during the

study for research and educational purposes. Before the researcher uses any of this information in the future, additional approval will be obtained from the appropriate ethical review committees.

IV. FINDINGS: The SCI Unit

The findings that relate to the descriptive aspects of the SCI unit, where this study was conducted, include the history of the building, the features of the SCI unit, and a description of the use of some of the facilities by the patients and staff members. In addition, a description of the role of the staff members in each area, a normal day for the SCI patients, and details on patients' and staff members' attitudes towards rehabilitation have been noted. The major findings concerning informants' experiences will be examined to reflect their similarities and differences using verbatim statements. To protect the anonymity of the subjects, all identifying characteristics have been altered or removed.

The History Of The Building

The SCI Unit was situated in a 298 bed capacity hospital in Western Canada. Originally built in 1954, it was designed for the treatment of tuberculosis patients. Improved anti-microbial therapy decreased the need for available tuberculosis beds, and by 1973, a need to change the patient population was perceived by the Hospital Administrators. Minor renovations were made to the building, and in 1973, health services were expanded to include Rehabilitation, Psychiatry, Respiratory, and Extended Care. The health services portion of the building is now being used for the treatment of long-term care patients (i.e., tuberculosis patients, SCI patients, and patients with respiratory ailments). The original maintenance services portion of the building housed the laundry facilities. At present, this space was occupied by the Physical Plant Paint/Carpentry Shop, Grounds Department, and Rehabilitation Services.

Architectural features of the building included an exterior that was finished in yellow brick cladding and consisted of four floors with a completed basement, while the maintenance services portion was a one floor structure with a partial basement and second floor. The interior walls were constructed of clay tile with plaster finish, and the ceilings

were made of acoustical tile cemented in place or painted plaster. The floors were either tiled or carpeted. An underground tunnel system linked the building to the main general hospital building.

The furnishings in the patient, visitor and staff lounges, patient rooms, patient and staff bathrooms, nursing stations, and administrative offices consisted of chairs, sofas, endtables, stools, light fixtures, desks, curtains, and wall hangings that had being acquired since the original construction of the building. A cozy homelike atmosphere had been maintained in this building.

While this building provided shelter for a variety of health services for the main hospital, the employees and residents were separated and, therefore, removed from the health care activity that took place in the main hospital. For example, if patients required spine x-rays or had to be seen by a medical specialist other than their attending physician, they were expected to go to the main general hospital. Having to depend on the staff and facilities that existed in the main hospital alienated, to some extent, the employees and residents.

Features Of The SCI Unit

The SCI Unit was located on the third floor of the building and was in the shape of a "T" (see Figure 1). The facilities and activities along each of the three main hallways separated each corridor into distinguishable wings.

The East Wing

Nursing Education Classroom

The nursing education classroom was situated at the far southeast corner of the building. This windowless room was located away from the main traffic on the unit. Furnishings consisted of tables, chairs, portable fluoroscopic X-ray viewing equipment,

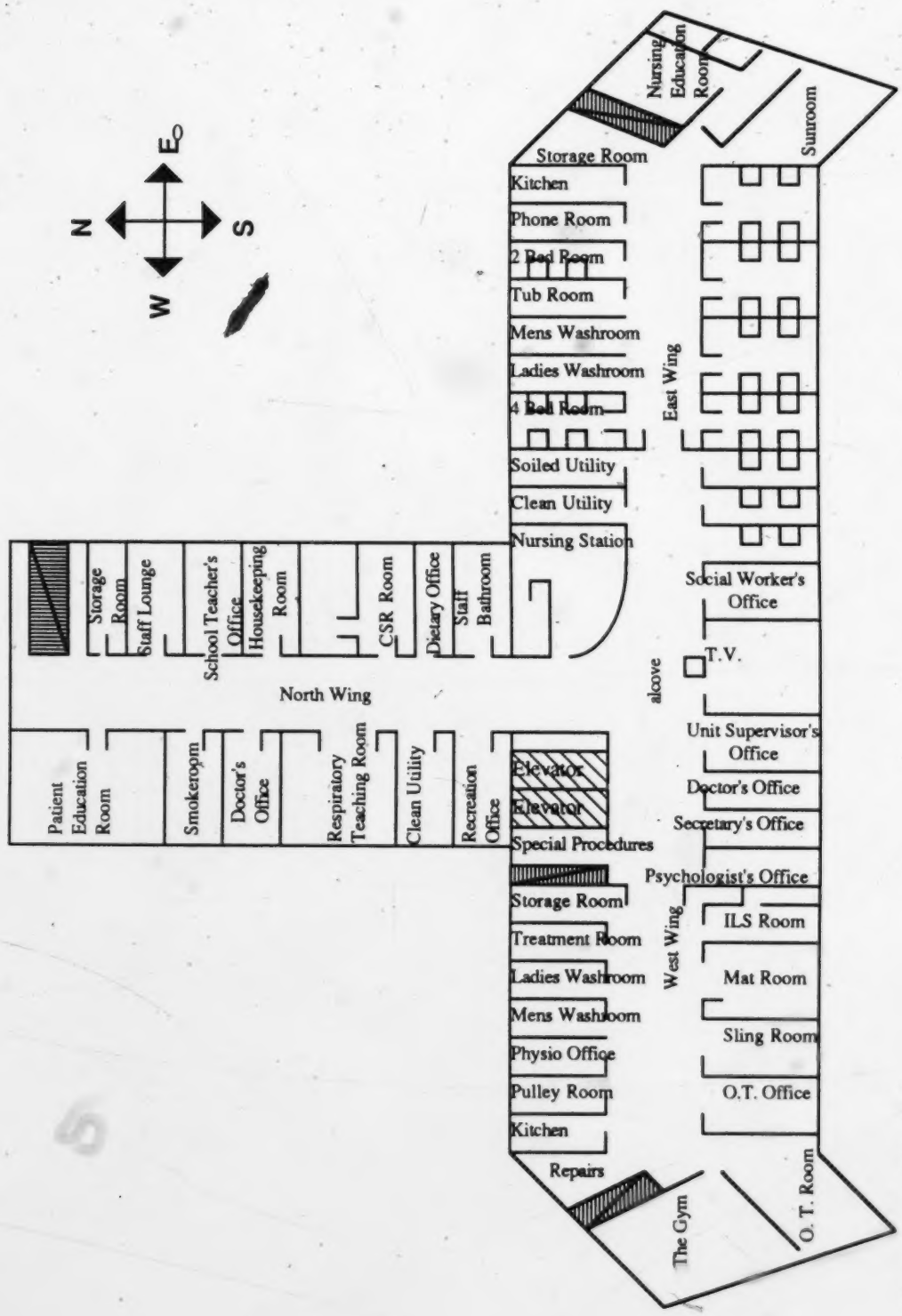

Figure 1. *The SCI Unit*

and a bulletin board (containing current reading materials related to the rehabilitation of SCI patients and notifications of upcoming conferences, workshops, and research presentations). Two additional rooms were connected to this classroom, one of which was the office space for the nurse educator.

The nurse educator planned, implemented, and evaluated nursing care, developed programs, supervised direct patient care, developed resource materials specific to SCI patients, organized inservices, and orientated new staff to the area. In addition, the nurse educator also assessed patients' needs, designed and initiated care practices to meet these needs, and coordinated instructional content for SCI patients.

In-house staff members, such as, the two physicians, the social worker, the psychologist, and the nurse educator, invited guest speakers, patients, their family members, and friends used this room for inservice education, family conferences, multidisciplinary rounds, and as a private place to meet with SCI patients. Inservices or workshops were held for staff and for health care employees from other institutions and organizations. Family Conferences for each patient were organized and chaired by the attending physician and included staff members from each of the multi-disciplinary departments located on the floor. For example, the social worker, the psychologist, the recreational therapist, the school teacher, the nutritionist, the patients' primary nurse, physiotherapist, occupational therapist, a representative from the Canadian Paraplegic Association, and the patient concerned attended family conferences. Generally, the patients' family members and friends were also invited to come. Consequently, family and friends met with the health team members and could ask questions about the patient's stay and the patient's ability to meet his or her needs, as well as, be involved in the patients' plans for discharge.

Every Thursday, multi-disciplinary rounds took place in the nursing education classroom. These rounds provided an opportunity for health team members to meet and

review their case loads, to become familiar with the ongoing activities of all patients and to plan and discuss interventions and modifications of patient care.

When a patient on the unit wanted to go to a private spot, this room was chosen:

> When I want to go to a place that is away from most of the people that are here, I usually go into the room at the very end of the hallway. They have conferences in there sometimes, but the thing that I like about going there is at least it's more private than anywhere else around here.

The Sunroom

Next to the nursing education room is an area that the patients, staff, and family members called "the sunroom." Because of large windows and the southern and eastern exposures, the room was bright and warm. The interior decor consisted of curtains, a wooden table, chairs, a sofa, a small black board, a stereo system, a video machine connected to a T.V., a phone, a lamp, plants, books, puzzles, plastic model pieces, crib boards, and playing cards.

Activities in this room were described as:

> Patient: In the sunroom you can sometimes hear the stereo blaring away or the T.V. that's in there is usually tuned to a movie; whereas, the T.V. by the nursing station is usually tuned to a sports channel. The patients usually go in there when they have visitors.
>
> Nurse: We hold patient-staff meetings once a month in the sunroom so that patients have input into how the ward is run. Sometimes we only get four patients attending these meetings, and sometimes we have up to twenty-two. The information discussed during this time is taken to administration for further approval. In the past, some of the issues brought up have been things like what the visiting hours should be, requests for funding to upgrade the equipment and supplies on this unit, where the T.V. by the nursing station should be placed, and the preparation of food. The recreational leader arranges for movies to be brought in every week and are also shown in the sunroom.
>
> Orderly Attendent: Most of the patients go to the sunroom to visit with their family or friends. If there is a special occasion

for someone, like a patient leaving or a birthday party, that's where they usually have it.

Family Member: We usually go to the sunroom to visit because there's more room there compared to the room that my son's in. Besides, it's pretty hard to have a private conversation in a room that has three other patient's in it plus their visitors.

Patient Rooms

Patient rooms were located on both sides of the east corridor. None of the four two-bed rooms and five four-bed rooms had a sink or toilet. Each patient was assigned to an adjustable-height, manually operated bed. A bedside table, an overbed table, and a built-in closet provided storage space for their personal belongings. SCI patients complained that this space was not adequate to house their possessions:

> The only thing that I can keep on my endtable, the table that's bedside my bed, is a radio. I have a few bottles of hand lotion and some candies sitting on the top, but other than that, I can't really bring anything else in because there isn't enough room.
>
> When you consider most of us stay here for six to eight months and have to share a room with other people, there just isn't enough room to bring in some of the stuff that I would normally have at home, like a small T.V., some posters, a few framed pictures of my family, and my ghetto blaster.
>
> I've got no place to put anything. In the closet, the bar is so darn high, that for us in a wheelchair, it is impossible to reach and get your clothes. So what you end up doing is asking the nurses to get them for you. If the closet was designed so that you could hang up, fold your clothes yourself, and put them away, then that would make a person like myself feel independent and be more in control of your situation.

The patients personalized their living quarters. One patient taped all of his greeting cards to the wall, and by the time his four and a half months stay was over, most of the wall space above his bed was covered. Others put up posters of skinny waisted girls in bathing suits, antique and sports cars, T.V. celebrities, and scenic mountain views; some kept drawings done by their children or grandchildren and photos of family members,

friends and pets in sight. Quilts, comforters, and afghans were placed on top of the bed linens of some beds. Gifts received from visitors, such as, potted plants, floral arrangements, fruit baskets, bouquets of balloons, and candy dishes, were closely packed together along several window sills.

Because of the original construction of the building, wall oxygen and suction outlets were not available. Patients who developed respiratory problems and required ventilation treatments were administered inhalation medications via portable machines that were kept at the bedside. Also, mobile suction equipment was used when needed.

Regulating the temperature in a room became a problem for staff when patients sharing accommodations wanted the heat set at varying degrees. For example, one patient situated in a four bed room would complain about it being cold, while another patient in this same room would request to have the thermostat turned down. Patients who wanted the heat turned up usually resorted to wearing more clothing during the day and covered up with extra blankets at night.

The windows were sealed shut and ventilation was poor. When a patient had a bowel movement, odors were a problem, despite the staff's efforts. They attended to patients' personal hygienic practices promptly, washed their thrombo embolic disorder (ted) stockings, disposed of dressings promptly, and regularly laundered the patients' soiled clothing. On occasion, however, these efforts were not successful at removing the odor. For example, one patient came back from a weekend pass and complained about having diarrhea for the past two days: "My stomach is no good. I can't eat. Every time I go to get up into my chair I mess myself." The nursing staff gave him frequent sponge baths in bed, a tub bath twice that week, had the linen on his bed changed daily, and his wheelchair was cleansed with a disinfectant every second day. The other three patients found the odor to be offensive and spent little time in their room.

Despite the use of aerosol sprays, bar deodorizers, and deodorizer drops on the sheets, the odor remained in this room.

The heads of the beds were not visible from the doorway of each room, and when an orderly attendant made rounds, he had to enter the patient rooms to check on the whereabouts of the patients. To maintain privacy, particularly at night, some patients kept the bedside curtains pulled around their beds.

The Social Worker

The social worker's office was directly across from the nursing station. The social worker received automatic referrals on every patient, and an initial assessment included information on the patients' psycho-social adjustment, work orientation, personal functioning, educational attainments, and vocational work experiences. This assessment also allowed the social worker to become acquainted with family members and surrounding community support networks.

The social worker said her role included helping people with their finances and insurances, acted as a liaison with community resource groups, and informed patients about entitled benefits. In addition, this staff member reviewed unemployment insurance, sick benefits, Canada Pension, and social assistance with each patient.

Patients' described the social worker, in much the same way as the social worker did:

> Is more concerned with the finances and getting funding to get special equipment that may be required.
>
> Usually gives you all the information that you need and the forms from all the different agencies and tells you where to go for what you need. Some counselling is done as well.
>
> Connects you with agencies, told me about programs out in the community, and checks into the benefits that people here are entitled to.

Nursing Station

The nurses' station consisted of a semi-circular counter and was used mainly by the unit clerks who answered telephones during the day, completed requisitions, paged staff members, patients, and visitors via an intercom system, arranged patients' appointments for things, such as, transportation, X-rays, blood work, consultations and examinations, and prepared the necessary paperwork for incoming and discharged patients. The unit clerks did not work on the weekends. Because the unit clerks' work area was accessible to anyone who passed by the nursing station, people frequently stopped to talk to them.

A wooden shelf on a counter had a number of separate compartments that provided storage space for any papers that were associated with a patient's stay. Below this counter were cupboards where the staff placed unit supplies, such as, staples, elastic bands, pencils, and additional paper. An oblong table was used by the nursing staff to chart. Behind this table was a bulletin board with news about the arrival of guest speakers, recreational activities for the patients, birth announcements, retirement functions, ward meetings, birthday and coffee parties, administration memos, and a rotation schedule of the staff members' shifts. A coffee pot and supplies of coffee, cream, and sugar were also kept on this table. An upright filing cabinet was to the left of this table and contained records of previous patient admissions.

All patients' charts were kept in three ring binders placed on a mobile rack. It was easy to identify a patient's binder as their last name was printed in bold lettering along the side of each chart. These charts never left the unit unless a patient was being seen by health personnel at the main hospital. A chalk board was positioned above the chart rack with the times that patients were scheduled for physiotherapy and occupational therapy classes noted on this board.

A "kardex" for each patient was kept on the only desk in this room. Each patient's kardex contained a care plan, including medical orders, nursing orders, medications, observations, and known allergies. The kardexes were used by the staff to assist in organizing the delivery of patient care.

Tucked away in the northeast corner of the nursing station were a locked cupboard, counter space, a sink, and more unlocked cupboard space. There was an array of medications inside the locked cupboard. One nurse per shift was in charge of preparing and dispensing the patients' medications. To the left of this area was a room where the staff kept their coffee mugs, coats, reading materials, and nursing manuals. If more than two people were in this room, it was difficult for them to move around.

The nurses' station was the most public place on the unit and was shielded by glass windows. Anyone was able to see into or out of this central area, and a concern was raised at a patient/staff meeting about the security of information located in the nurses' station. Because nurses felt many patients who frequented this spot knew, at times, more about what was going on in the unit than they did, some of the nursing staff suggested that the T.V. by the nursing station be moved to another location.

Some of the SCI patients said that they positioned themselves at the nursing station because they wanted to be visible to the public. The patients said that they enjoyed watching people and observing the reactions they received from others. Also, the patients indicated that it was comforting to be positioned at this location because of the nurturing they received from staff members.

The shift report for the nursing staff working nights and days was held at the nursing station, and the evening report was delivered in a room located in the north wing. During the shift reports, each patient's daily activities on the unit were discussed by the staff. When the SCI patients were near the nursing station during shift report, they could hear what was being said by the staff; consequently, they felt that these reports

jeopardized the confidentiality of information on the unit. The patients said that they found out about staff members attitudes towards them, news regarding their family and friends, and information about the staff's personal lives by being at this location. They suggested that it would be more appropriate to hold the shift reports in a room where others could not observe and hear what went on.

The Nursing Staff

The nursing staff consisted of one unit supervisor, 10 registered nurses, 11 registered nursing assistants, and relief and rotating nursing student personnel. The unit supervisor worked the day shift from Monday through Friday and had administration responsibility for the patients, staff, and physical facilities of the nursing unit. The nurse-manager, who had a calm, positive, and realistic manner with a quiet sense of humor, set the tone for this unit. She was recognized as the leader by the nursing staff, and she had the respect of the physicians and the support of the other health team members.

Most of the registered nurses on the SCI unit were graduates of hospital diploma schools, and a few of the RNs had completed baccalaureate nursing programs. All the RNs were expected to preform all levels of nursing care required by patients, to be in charge of the nursing unit once they had received "an orientation to the desk," and to perform primary nurse activities. The primary nurses carried a patient load of up to five patients, understood the patient's needs, and interacted with each of the interdisciplinary health workers assigned to these patients. This involvement by the primary nurses placed them in a position to be aware of patients' progress during rehabilitation and to revise the nursing care accordingly. Some of the RNs worked permanent days, while others worked only the evening or night shift.

Eight of the 11 registered nursing attendants were males, and they preformed a variety of activities on the unit, including catheterizations, bowel routines, and condom changes for the male patients. For the most part, these individuals were graduates of a

one year program and were prepared to work under the supervision of registered nurses. There were usually two full time RNAs on the day shift, two on the evening shift, and one on the night shift. Considering the male RNAs were the individuals who participated in most of the patient transfers and gave the SCI patients tub baths, all of the female nursing staff considered them to be valuable team members.

The relief staff were principally RNs or RNAs and either they were permanently assigned to work on the nursing unit or worked as floats on other units in the building. When a staff member was ill, the workload increased and if a scheduled work day was forthcoming, these staff members were requested to fill staffing quotas.

Nursing students who rotated through this unit as part of their senior nursing practicum were from a hospital-based program. The experiences of student nurses were controlled by the nursing staff. If the students requested management responsibilities or wished to be assigned to a SCI patient who required complete care, the staff organized these experiences for them. For example, students would pass out all the patient medications or assisted patients with their bed baths, dressings, and meals. The nursing students were perceived by the staff as essential and necessary health team members. The program that prepared the students for registered nurse licensure had an instructor who supervised their direct patient care and assessed the students' level of competency.

There were three nursing care systems operating simultaneously on this unit: primary, team and functional nursing. Most of the staff members indicated, in interviews, that all three nursing approaches were necessary. One of the staff members said, "We need them all for different reasons. We need the primary nursing because every patient needs his nurse for completeness of care." Another staff member said, "We have team nursing because there are things like baths, dressing changes, turns, and changing the linen that are carried out by the staff successfully in this manner." All the nursing staff felt

that functional nursing was needed because "it's a heavy ward" and "we need our orderlies help all the time."

Clean and Soiled Utility Rooms

The utility rooms were used by the nursing staff to obtain or dispense supplies. The SCI patients rarely entered these areas alone because they felt both rooms were off limits; however, they were aware that if they needed a dressing changed, to be catheterized, or some incontinent pads, the staff got the articles needed from these rooms. The most common complaint by the staff with respect to these rooms was there was not enough storage space; consequently, they kept some supplies in other areas, such as, the supervisors' office, the nursing station, and the phone room.

The Women's and Men's Washrooms

The washrooms had mirrors, two sinks, and toilet stalls, with a sink, toilet, and bathtub situated at the back. The washrooms became crowded if more than two patients used these facilities at the same time, and the SCI patients had difficulty getting their wheelchairs in and out of the toilet stalls because the doorways were barely wide enough. Considering most of the patients used these rooms for their a.m. and p.m. care, there was usually an odor present, the remains of hair, toothpaste, and shaving cream could usually be found in the sinks, and the mirrors were always covered with spots. The patients said that the location of the bathrooms was not convenient, needed improvements, and, perhaps, would be more practical if these facilities were inside patient rooms. One of the patients said,

> Using the bathroom can be a morning marathon because eveyone wants to use them, so what happens is people wait in line. What's even worse is if you happen to have an unexpected bowel movement in your chair, and you rush to the bathroom to get yourself cleaned up, and there are already a couple of guys in there. It's really embarrassing. They need some large bathrooms that could be used in private at the same time instead of it being a communal event.

The SCI patients also said that the bathroom facilities affected how they felt about themselves. When the patients had to line up to use the bathrooms, they felt like second class citizens and became angry about their bodies not functioning as they did before their injury. The patients indicated that the lack of ease with using the bathroom facilities promoted self-disgust and increased their frustration with having to live with physical limitations. Most of the SCI patients said that these facilities made them feel "less human" and stigmatized.

Tub Room

Two bathtubs were located in a room the staff called the "tub room." All the patients were usually transported to this room by stretcher, and the male RNAs normally assisted them with their baths. The staff called the bathtubs "century tubs," and they operated like a jacuzzi. When the tubs were filled with water and the jets were turned on, the water was propelled around the tubs. The patients liked the feeling of the water moving against their bodies, and they said that it helped them to relax, improved their circulation, and relieved their aches and pains. SCI patients had a bath twice a week, and they felt this was not enough:

> I usually wash up in my room in the mornings; otherwise, I get a bath twice a week, which isn't enough. Before my accident, I showered every day.
>
> When I void, I sweat. That's my condition. So for me, I need a bath pretty well every day. Otherwise your hair and body get so itchy.
>
> It feels so good when I have a bath. I feel refreshed and more presentable to people when I do. We only get a bath twice a week here, and it sure isn't enough. I feel better about myself when I get my hair washed and soak in the tub because after my O.T. and physio classes I get all sweaty.

Phone Room

The patients used the "phone room" to make personal telephone calls. They called their family members and friends, made arrangements to socialize with others in the

evenings and weekends, and sometimes ordered food from this location. The features on the phone made it accessible for use by both quadriplegics and paraplegics.

The Kitchen

The facilities in the kitchen consisted of a sink, fridge, counter and cupboard space, and a microwave oven. Inside the fridge, there was a variety of snacks and beverages for the patients if they got hungry between meals, and this food was replenished daily by the staff from the dietary department. On movie night, the volunteer usually cooked popcorn in this room. If the patients ordered food in and there were leftovers, they usually stored them in this fridge.

Storage Room

Extra stretchers, wheelchairs, commode chairs, and siderails were kept in the storage room. The patients seldom entered this area.

The West Wing

Unit Supervisor's Office

The room that was situated next to the T.V. in the alcove of the west wing was referred to by the staff as the "unit supervisor's office." There was a large wooden desk, cabinet files, a phone, cupboard space, and equipment from the nursing station housed in this location. The nursing staff used this room to eat their lunch, use the telephone, and read a book or magazine. Most of the time, the door was kept open, and staff considered it appropriate for them to make use of this space.

The Chief Physician

The chief physicians' office space was situated next to the unit supervisor's office. The role of this physician was to see the SCI patients when they were in intensive care, build a rapport with them, determine what their rehabilitation needs were, and inform the patients about their transfer to the SCI unit. When the patients were transferred to the unit, this physician made medical rounds every week to see his patients separately and to

assess what changes were needed with respect to their care as they progressed through the rehabilitation program. The chief physician said, "The primary goal here is to assist the patients in regaining functional abilities that will allow them to live independently. Most of the patients are men because the ratio of males to females that are injured is usually three to one."

The Secretary

Next to the doctor's office was office space for the only secretary on staff. This secretary was considered young and attractive, was well liked by the SCI patients, and always welcomed people in a warm and caring manner. The door to this room was usually kept open, and the patients often dropped in to say hello and chat with this person. Regardless of how busy she was, this staff member took the time to speak with whomever came to see her. The secretary performed a variety of activities, such as, filing patient records, answering the phone, booking patient appointments, completing necessary forms, and updating records to facilitate the physician's work.

The Psychologist

The psychologist's office was adjacent to the secretary's office. During the week, the psychologist met with patients in the hallway and, upon request, saw them in his office. Most of the SCI patients said that this staff member provided counselling services and was there to assist them with the changes they experienced resulting from their injury. Some of the most difficult changes the patients identified were the limitations of mobility, role reversals with their spouse, family members, or girlfriends, issues of sexuality, and altered body images. To manage a severe impairment both in the hospital and after discharge, the psychologist felt patient areas that required sensitive exploration were interpersonal relationships, psychological attributes, cultural factors, environmental factors, financial resources, and vocational training.

The psychologist said that his role on the unit included counselling, being a resource person, conducting personality tests, and giving specific treatments, such as, psycho therapy or behavior modification. This staff member also said, for the most part, that he intervened when a patient was not "helping himself," or was "not cooperating with the program." The psychologist felt rehabilitation was a "living process" and believed SCI patients faced many life changes as a consequence of their injury. During an interview, the psychologist commented on patients' stay on the unit and said, "At the beginning, they are very apprehensive about what's going to happen. As their stay increases, they voice their opinions, and before they are leaving, most of them are scared and unsure how they will manage in the outside world."

Independent Living Suite (ILS)

The independent living suite (ILS) was a one bedroom apartment suite that was fully furnished with a stove and fridge, sink, table and chairs, microwave oven, cupboards, chesterfield, a bathroom, a bed, and dresser drawers. Inside the cupboards, there were a variety of kitchen accessories, such as, a mix master, serving bowls, baking pans, and a toaster. Some of the utensils were custom made to increase the patients' ability to use them. For example, the patients used a long wooden handle with a round knob at the end to turn the burners of the stove on or off. Some of the knives and forks had special circular handles on the ends and the patients wore wrist cuffs so they could get a better grip on these eating utensils when they baked, cooked, and ate food. Inside the bathroom was a pole that extended from the ceiling to the floor so that patients could position themselves on the toilet. A cushioned bath seat provided a means for the patients to enter and leave the bathtub. This equipment enhanced the SCI patients' ability to function independently. Prior to discharge, some of the SCI patients lived in this room to determine if they could manage their day-to-day activities, such as, transferring into and out of bed, bathing, preparing meals, and dressing themselves. The use of the suite was

controlled by the occupational therapy staff, and these individuals monitored the patients' progress while they resided in this location.

The Mat Room

Three large floor mats were situated in the mat room. SCI patients entered this area for physio therapy classes, and they learned how to roll over, turn, transfer from the mats to their wheelchairs, and participate in daily stretching exercises with the assistance and guidance of physiotherapists. Individual treatments were conducted in this room; group and individual physio classes were held in the gym. All the patients spoke about their physio classes in terms of progress or setbacks they experienced, and they indicated this aspect of their rehabilitation was hard work:

> Some people think that just because you're in the chair all the time your doing nothing. Well I'm working 24 hours a day. When I go to my physio and occupational therapy classes I work damn hard. It's not easy trying to maneuver yourself around without the use of your legs. Some days are good, when you can see progress in your movements or when you do something that you have never done before. That's progress, but you also have setbacks when you get sick or your spasms increase. These times are really disappointing. At the beginning of classes, you tucker out pretty fast, but as you build your resistance, I found my strength and endurance also increased.

> If I had to describe what it's like for me during physio I'd have to say a lot of hard work. I usually have to go and lay down after it's over. The classes only last for an hour in physio and the same for O.T. (occupational therapy), and this is not long enough. Sure it's work when your doing it, but you have to do a lot of exercises on your own because there just isn't enough staff to see the patients any longer in the day. You have a good day when something novel happens, like transferring with a transfer board from your chair to the mats and you don't have any spasms or you turn over for the first time. Yet when I try to do something that I have done before, I get really down. Most of the time you see slow progress with what you can do, and there are a lot of setbacks.

The Sling Room

One floor mat, a tilt table, and sling equipment were housed in the sling room. The floor mat was used principally for the same purpose as the mats in the mat room. Under the supervision of a physiotherapist, patients were placed on the tilt table, strapped in with velcro belts, and placed in a standing position to increase their peripheral circulation and get accustomed to an upright position. The sling apparatus consisted of ropes that were attached to a pulley devise so patients could stretch their arms and build their tricep or bicep muscles. The physiotherapists said that graduation from sling classes to pulley classes depended on the SCI patients' level of endurance, range of motion, and the functional abilities of their upper extremities.

Occupational Therapy (O.T.) Room

Each SCI patient was assigned to an occupational therapist for the duration of their stay, and they entered the occupational therapy (O.T.) room when they were booked for these particular classes. There was a variety of equipment in this room used by the patients to strengthen their upper extremities and improve their fine motor movements. As the patients went through their routines, a radio was tuned to a station that played top 40 hits; also, they were able to socialize with others, and the patients indicated that this arrangement promoted a "fun-at-work" atmosphere among patients, staff, family members, and friends. Family members and friends would casually stroll into the room if their relative or friend was exercising. As the staff and patients became familiar with each others' visitors, they would welcome them into the room and continue on with their activities. The SCI patients liked their occupational and physiotherapy classes because they perceived them to be a necessary and important means for acquiring skills to cope and manage their lives in the future.

Occupational Therapy (O.T.) Staff

The occupational therapy (O.T.) staff consisted of full-time and part-time members, one occupational therapy assistant, and students who were enrolled in a university-based occupational therapy program. A normal day for the O.T. staff began with assisting and instructing the SCI patients in activities of daily living. These activities involved teaching the patients techniques related to feeding, grooming, bathing, and dressing themselves. It usually took up to two hours for some of the patients to complete these tasks. After this instruction, the therapists wrote in the patients' charts, compiled statistics regarding their involvement with direct and indirect patient care activities, and mapped out program events in their department. Just before lunch, most of the therapists saw patients on an out-patient basis. The therapists took one hour for lunch and returned to the department for more scheduled appointments with patients located in the building. The patients could choose the time they wished to have their O.T. classes provided all the patients did not request to be seen at the same time. The therapists were flexible about rearranging these appointments if the SCI patients were ill, refused therapy, or had a conflict in class scheduling. After the end of their work day, the staff were expected, on occasion, to participate on committees, such as, quality assurance, audit charts, or hold their own staff meetings. This department was closed on the weekends.

The therapists said that their role on the unit included assessing the SCI patients according to a problem list that constituted fracture management, patient education, and sexuality. These staff members also ran a series of classes for the patients on topics of anatomy and physiology, fertility, sexuality, and communication. Guest speakers were invited for some of these classes, and they informed the patients about topic areas, such as, residential aid placement services, handicapped housing resources in the community, travel tips, vocational and employment opportunities, and financial planning.

Most of the O.T. staff said that they developed close relationships with the SCI patients because all the patients usually car.e to one "treatment room," classes were conducted in a "group situation" and they were involved with the patients' rehabilitation program on a daily basis. The occupational therapists felt that having a number of individual therapy classes in one room facilitated a "team spirit," helped build moral and support between the staff members and the patients, and enhanced communication between all participants. These staff members also said that creating a relaxed atmosphere in the department promoted SCI patients' rehabilitation because patients felt more comfortable with their routines when they were permitted to speak freely, tell jokes to one another, and do their exercises "at their own pace." One of the therapist's commented on her experience with the patients and said,

> Most of the patients confide in us because we help them with day-to-day activities like getting dressed, showering, and we see them on a regular basis during their rehabilitation. They confide in us about the problems that they have about coping with the permanency of their injuries.

The Gym

Three floor mats similar to the mats used in the mat room and sling room, plus a set of parallel bars, an exercise bike, arm and leg weights, wooden blocks, and an assortment of other equipment were used by the patients during physio classes in the gym. Individual treatments went on simultaneously, creating a group arrangement of patients and physiotherapists. In time, as the SCI patients and staff worked out and become familiar with the patients' physical strengths and weaknesses, close ties developed between them. They called each other by first names, and sometimes, nick-names were used, such as, "Lee," "Stubbies," and "Stu." When the therapists saw a patient struggling more than others to complete similar tasks, they provided moral support and encouragement by saying "keep going," "you can do it," and "don't give up." It was a common occurrence for patients to drop by and observe the progress of their roommates,

offer words of advice if they experienced difficulty completing the activity they were involved in, or simply to tell a joke they had recently heard. A radio was also on, most of the day, in this room.

Repair Room

The occupational therapy assistant utilized the repair room to repair any equipment for the patients. If an appliance, such as, a brace or eating utensil, broke or required adjustments, this staff member did the repair. For example, a sewing machine, tools, and garment accessories were kept in this room.

Kitchen

Staff members from the occupational therapy and physiotherapy departments encouraged patients to use the facilities in the kitchen. Participation by patients in this activity was considered to be an aspect of their rehabilitation program. When a patient cooked a meal, they usually invited other patients, staff, and family members to join them in eating the prepared food. The patients took great pride in their endeavors to make appealing meals and gave careful consideration to the presentation of the food. A stove, fridge, sink, and special cooking appliances and utensils enabled SCI patients to be involved in activities associated with the art of cooking.

Pulley Room

Next to the kitchen was a room the staff called the "pulley room." When patients went into this room, they said that they were going to do "pulleys." Most of the patients considered their pulley classes to be "hard work." A physio aide was responsible for coordinating patient activities that were meant to improve their upper body muscles.

The third radio on this wing was located in the pulley room, and having this radio on created a relaxed environment while the patients attended these classes. SCI patients wheeled themselves by the pulleys, and the physio aid connected the "stirrups" to their arm bands or passed the "stirrup handles" to the patients so they could hold onto

this equipment. Several patients could participate in pulley classes at one time, and they said that when there were other patients present they felt compelled to work harder on their routines.

Talking about their experiences in the pulley room, SCI patients said,

> First there is a stirrup like a horse, and you hook this stirrup that is connected to a rope onto an arm band that you wear. The rope goes around a pulley and down to the weights on the floor. When you pull your arms forward the weights that are attached to the ropes goes up. We do these exercises in our chairs.
>
> When I got here, they started me on the sling. I got stronger, then I went to pulleys.
>
> When I do pulleys, I pull weights and strengthen my upper body. There are different exercises every day, so you're strengthening certain muscles everytime you do this. Most of the pulley classes are for half an hour.

The Physio Aide

The physio aide said her role on the unit involved conducting different exercises for the SCI patients each day of the week. For example, on Mondays, the physio aide called her classes "diagonal day." When the patients went through their pulley routines on this day, they put their wheelchairs sideways to the pulleys and participated in exercises this staff member called "D1" and "D2 selection." The physio aide said that "straight" exercises were performed on Tuesdays and Fridays. When the patients came to pulley classes on these days, they would position their wheelchairs in front or behind the equipment and do their pulley routines. Most of the patients said that they did not enjoy pulley classes on Wednesdays because it was "endurance day." The physio aide indicated that on Wednesdays she would cut the weights in half, and the patients would do up to 100 attempts in their pulley routines. Usually, the patients did 30 pulls per exercise on the other weekdays. The physio aid said that all the SCI patients regularly attend their classes.

Physiotherapy Staff

The physio department consisted of full-time and part-time physiotherapists, students who were from a university-based certified therapist program, and one physio aide. The physio office was situated between the pulley room and the "ladies'" and "mens'" washrooms.

The physiotherapists' day began with paper work and treating SCI patients or other patients in the building who were experiencing respiratory problems. As most SCI patients were occupied with personal care at the beginning of the physiotherapist's day, physio classes did not usually begin until 0900 hours, when a physiotherapist conducted walking classes for those patients who could walk with the aid of a cane or walker and those in the initial stages of weight bearing. Between 1000 and 1030 hours, therapists wrote progress notes in patients charts, compiled statistics dealing with patient care, and ordered equipment, such as, pulley sets and transfer boards for patients to take home when they were discharged or were on weekend passes. From 1030 to 1130 hours, the physiotherapists saw patients on an individual basis, had lunch for an hour, and continued therapy activities until 1630 hours. This department was usually locked after hours and on weekends.

The normal case load for a therapist was four patients, and the assignments were evenly distributed among the physio staff. Each patient was with a specific therapist for an hour and could negotiate their own schedule. All the staff in the occupational and physiotherapy departments felt that their classes complimented each other and were essential to the rehabilitation of SCI patients. Some of the physiotherapists said,

> One without the other doesn't work because the things that the occupational therapists work on with the patients assist them to perform certain activities during their physio. Neither is more important than the other because the purpose of rehabilitation is to develop a program that will be suited to most needs of the patients so that they can, in time, be self-reliant.

> We may teach them how to roll over, sit up, and balance, and then O.T. will take over and teach them how to dress themselves. The patients need to master certain skills first in both areas to progress onto more difficult things.
>
> The progression of the patients is usually slow and frustrating at times. When they come in and leave, they are like two different people. It's physical work, but I also find it challenging because these people have had so much taken away from them, and without the assistance of all the departments that are here, the SCI patients potential to lead productive lives would be decreased considerably. The occupational and physio departments are not separate entities but work closely together.

The Women's and Men's Washrooms

The women's (referred to as the "ladies'") and mens' washrooms were next door to one another, had the same features as the washrooms in the east wing, and were primarily used by the patients when they attended classes in this area. In comparison to the "lived in" appearance of the washrooms at the opposite end of the hallway, these washrooms were tidy, there were no odors present, and the taps and mirrors on the wall were always clean. The patients said that they only used these rooms when they felt they "couldn't hold it any longer."

Treatment Room

Physiotherapists conducted ultra-sound treatments on SCI patients in a room they called the "treatment room." The procedure usually took five minutes, and some of the individuals that received this treatment said it was not painful and felt like a gentle vibrator against the skin. According to the physiotherapists, this particular treatment decreases inflammation of the tendons and allows SCI patients to experience increased ranges of motion. These treatments were delivered according to the individual needs of each patient.

Storage Room

All the wheelchairs that belonged to the physiotherapy department were stored in the storage room. The patients were permitted to use these wheelchairs in order to find the one that best suited their needs. Depending on the features, patients classified the

wheelchairs as run of the mill, middle of the road, and cadillac styles. The patients also said that there were wheelchairs that were best suited for indoor and outdoor activities, sports events, and travelling. According to the SCI patients, wheelchairs made of fiberglass were the best chair to buy because they were light in weight, could easily fold up and fit into the back seat of a car or trunk, had detachable parts, and could be used both indoors and outdoors in all kinds of weather conditions.

Special Procedures Room

Emergency equipment for the unit was housed in the special procedures room. The equipment in this room included a crash cart, linen supplies, a treatment table, and bandages. The only people that entered this room, during the conduct of this research, were a few staff members because they needed some supplies.

Elevators

There were two elevators near the nursing station. In their spare time, the patients positioned themselves near the alcove and observed the comings and goings of individuals who used these elevators. Most SCI patients said that it was entertaining to watch the activity that took place at this location, and they said it helped them to pass time. When they wished to go to other areas in the building, SCI patients generally had no difficulty operating the elevators.

The North Wing

Recreational Therapy Staff

Staff members that worked in the therapeutic recreation department were responsible for organizing leisure activities for SCI patients. The leisure activities organized by these staff members were considered part of the patients' rehabilitation program. Leisure activities included socials held in the auditorium one floor below the unit, shopping at the malls, seeing professional hockey games in person, and visiting some of the tourist attractions in the city. A balance between work and play activities is

beneficial for a persons physical, psychological, and social well-being; therefore, SCI patients were encouraged to participate in events that would help them maximize their capabilities and to cope with current and anticipated situations. Such coping strategies implied the development of new or modified social skills. Participation by SCI patients in recreational activities was a means for them to socially interact with others, which helped restore their sense of worth, body image, individuality, sexuality, and spiritual well-being.

Doctor's Office

There was another physician on staff who worked in collaboration with the chief physician. This staff member's office was located between the "respiratory teaching room" and the "smokeroom." All the staff called this room the "doctor's office," and the only individual that usually entered this room was this physician.

Smokeroom

A designated smoking area for all the patients in the building and their visitors was located on the SCI unit, and it was called the "smokeroom." The contents of the smokeroom included a shuffleboard table, a couch, chairs, a T.V., a bookshelf, a plant, and ashtrays. This room was usually heavy ladened with smoke fumes, which penetrated the hallways. Attempts had been made by the staff to provide a means of circulating fresh air in this location by the placement of ecologizers; however, their efforts were defeated as these machines were unable to filter the amount of smoke in the air. Individuals that smoked principally used this room and, over time, some non smoking SCI patients became smokers, particularly if they were between 17 and 25 years of age.

Patient Education Room

SCI classes taught by staff from the physio and nursing departments were conducted in the patient education room. The content of these classes constituted the anatomy and physiology of the body, with emphasis placed on the functions of the spine,

bladder, bowels, lungs, sex organs, wheelchair management, and skin care. When approximately five to six new patients arrived, the staff conducted these classes everyday from 1300 to 1400 hours for one week. SCI patients were expected to attend these classes as the staff felt that this information was important for providing them with alternative ways of managing their predicament. Most of the young SCI patients were reluctant to discuss their fears and apprehensions, while the middle-aged and older patients spoke more freely about their concerns. All the SCI patients feared that they would never walk again and hoped that the damage to their spine could be repaired.

Staff Lounge

Evening shift report took place daily in the staff lounge, and the only individuals who used this room were the nursing staff. The unit supervisor conducted this shift report during the week, and on weekends, the nurse that was in charge of the nursing unit was responsible for informing and updating the oncoming staff about the patients' activities in the past 24 hours. Nurses also used this room to relax, eat their meals, or read a magazine on their breaks. Two couches, chairs, a table, a fridge, and an endtable were situated in this area.

The School Teacher

There was one school teacher on staff who was responsible for providing educational services for the SCI patients who wanted to continue their school activities while they were in the rehabilitation program. The patients chose whether they wanted to participate in any course work. Although they were aware of the option to continue or commence educational studies, only two SCI patients were involved in school activities during this study. The patients said that they were not aware of all the activities of the school teacher because they had less contact with this staff member than with others, such as, the physio and occupational therapists. All the SCI patients said that they developed closer ties with staff members who were involved in their rehabilitation program on a daily

basis and felt closer to these individuals because these staff members observed their progress and setbacks during rehabilitation.

The school teacher said that his role on the unit included phoning and receiving calls from people, getting materials the patients needed, such as, books and correspondence packages, picking up and delivering these materials to the appropriate agencies, and conducting individual tutoring sessions. This staff member also said that he introduced himself to the patients when they arrived on the unit, informed them about the educational resources that were available to them, and felt much of his time was spent in his office carrying out administration duties.

Central Supply Room (CSR)

Wash basins, sinks, bedpans, and bedside supplies, such as, needles and dressing trays, were placed in a room the staff called the "central supply room." One staff member who used this room worked in the housekeeping department. This individual cleaned some of the SCI unit supplies and recirculated them for future use. The patients never entered this area.

The Housekeeping Staff

Several housekeeping staff worked on the SCI unit. Some of these staff members said that their role included washing the floors, bathrooms and kitchen facilities and dusting the window sills and bedside tables in the patient rooms. Some of the housekeeping staff were asked to explain what their experiences were like with SCI patients. They said the patients tried their hardest to get back as much functional ability as possible and mentioned it took a lot of hoping and a lot of persuading for most of the patients to overcome their limitations. All of these staff members said that once the patients became familiar with them they usually told the housekeeping staff their story. Most of these staff members mentioned they felt that the patients confided in them because they did not determine the rules to be followed on the unit.

The Dietary Staff

A part-time dietician, a full-time dietary technician, a food clerk, and a nutritional supervisor worked in a room the staff called the "dietary office." These individuals worked in the department of nutrition and food services and were knowledgeable about the nutritional aspects of patients. The food habits of SCI patients generally varied, and these staff members often were faced with the difficult task of providing well-balanced meals and individual requests for special snacks. SCI patients complained about the food in the cafeteria, and they raised concerns about the repetition of meals and the times the meals were served. In order to deal with patient complaints about the food, the nutritional staff had organized a food committee. The food committee, consisting of staff members and patients, evaluated the meals and suggested special items specifically for the SCI patients, in order to offer a wider selection.

Staff members in this department said that it was difficult to satisfy all patient food requests considering the variation of age groups. The younger patients, generally between 17 and 35 years-of-age, asked to have more "fast foods" integrated into the menu; whereas, the older patients, over 60 years-of-age, requested "bland meals." All of these staff members said that team work was important if they were to be effective and beneficial to every patient. For example, they said that the nursing staff did calorie counts for patients, and this activity assisted them to plan and organize patient meals; and, in turn, if patients' weights were controlled, this facilitated their progress during rehabilitation.

A Normal Day For The SCI Patients

Wake-up Call

During the week, SCI patients woke at approximately 0700 hours when the kitchen staff came into their rooms and replaced their old water jugs with fresh ones. The patients said that these staff members entered their rooms like clockwork:

> The day starts at seven, when they sneak in before it's light and change your water. It's just like clockwork when these people come in. You don't even have to have a watch to know that it's seven in the morning.

> My day usually starts at seven in the morning. The ladies bring a cart down the hallway and go around to all the rooms where the patients are and change the water jugs. They take the old jugs away and replace them with jugs that have fresh water. Sometimes when they take the jugs away, things drop on the floor, and you can't help but get awake. You know when these people come in it's seven because they come around the same time every day.

After the kitchen staff made their rounds, nursing staff assisted SCI patients with their morning care. On the weekends, they were permitted to sleep in as long as they wished. To avoid the line up for bathroom facilities, some SCI patients got out of bed at 0600 hours.

Getting Regulated

Patient morning care involved such activities as catheterizations, bowel routines, tub baths, sponge baths, showers, heparin injections, and getting dressed. Of these activities, one of the most difficult for SCI patients to achieve was regulating their bowels. Several strategies were employed by the staff to assist patients in achieving this goal. SCI patients were given rectal suppositories, digitals, and laxatives, such as, Surfak® and Senekot®. Explaining these experiences, SCI patients said,

> My bowel routines are every two days. I get laxatives every day, and I know one of them is called Surfak®, and every two days the orderlies give me a suppository. I usually get pretty good results with these things. Getting constipated is one of the worst things. When this happens I don't eat properly, my stomach becomes upset, and I can't do my

> exercises properly in O.T. or physio because I just don't feel well.
>
> When you get a digital, a person places a disposable glove on their hand, inserts their middle finger into your anus, and rotates it around this area. It helps to stimulate your bowels. It bothered me a lot at first when I had to have this done because it's an invasion of your privacy, of your body parts. It's not very pleasant, but it has to be done.
>
> When you first come here, they place you on a night routine and then progress to a day routine to make sure when you go out and socialize you are less likely to have an accident with your bowels. Some days you only need a sup (suppository) and a dige (digital). Usually you need a sup and two to three diges to really get you emptied.
>
> There are some days when you can sit on the can and your bowels move within five to ten minutes and you're done. Then there are days when you can take up to one and a half hours to finish your bowel routine. It all depends.

When SCI patients arrived at the unit, most of them tired easily and needed to rest after their morning routines. In time, they became stronger and could manage to stay in their wheelchairs until bedtime. SCI patients said that after their injury doing simple tasks, such as, taking a shower or shaving, was tiring. Taking short rest breaks during the day helped them to overcome their moments of fatigue and to proceed with their rehabilitation program.

Meals

Three meals were prepared by the kitchen staff each day. Breakfast was served between 0745 to 0830 hours. All SCI patients ate breakfast in bed. Lunch and supper meals were served in the cafeteria, located one floor above the unit, between 1130 and 1230 hours and 1630 and 1730 hours. If a patient was ill, the staff brought his or her meal to the bedside. When the patients went to the cafeteria, they usually ate in the same areas. The young and middle-aged SCI patients, all under 65 years-of-age, usually chose to sit together at one particular table; whereas, the older patient group sat by themselves at other locations in this room. SCI patients that ate together eventually established designated spots, and the patients that had been there the longest usually positioned

themselves towards the end of the table. For example, if a new comer happened to place himself where another patient normally ate, he was reminded of this by the other patients: "Jack sits there," "You're in Brian's spot," or "Wait till Bill comes and sees you're in his spot." One of the patients described the cafeteria and said,

> We go up one floor to the cafeteria and have our lunch and supper there. We use the elevators to get to the cafeteria. It's like a self-food bar. You wheel up and get your forks or knives. Then you place your tray down on the counter and help yourself to things like salads, juices, and desserts. If you want hot food, then there are usually two ladies standing behind the counter to give you something off of the main menu. There's a milk machine and water machine if you want. Further down the line is a coffee machine.

Because they had to line up for food, SCI patients said that the cafeteria reminded them of a prison camp. They equated this behavior with the poor, imprisoned, deprived, and underprivileged. Usually there were staff members in this area who fed some of the patients who had limited use of their arms. A few of these patients commented on this particular experience and said,

> You get used to it, but you never like it. It's like a baby. Sometimes you are trying to swallow your food, and they want to give you more. You have to set the pace because no one knows what it's like to be fed unless you go through that experience yourself.

> At least I can talk. When I'm fed, I ask to have some milk or choose whether I want my potatoes first and things like that. I can't imagine not being able to say whether someone is feeding you too slow or too quick. At least I have some choices at meals.

SCI patients felt that they lacked privacy if staff members were present at their meals. In order to gain control of their meal situations, some of SCI patients would attempt to flip their eating utensils onto a food cart. This behavior appeared to serve as a coping mechanism for maintaining their dignity, pride, and self-respect in a situation where there was no choice in when or where to eat.

The Classes

Between meals, SCI patients "worked out" in their rehabilitation classes, such as, physio and occupational therapy, attended scheduled appointments, and met with staff members, such as, the dietician, social worker, and psychologist. The patients generally felt that their time during the day went by quickly; however, they did not feel this was the case in the evenings. SCI patients found the evenings lengthy unless something novel happened, such as, touring a building, seeing a show, or playing a board game.

Killing Time

When SCI patients were not attending classes, did not have any appointments, and were not required to be at any particular place, they said they were "killing time." From the patients' perspective, killing time constituted their free time with no planned activities. The amount of free time they had depended upon the length of time it took them to go through their daily routines. Patients had more time to kill on Saturdays and Sundays because they did not attend any rehabilitation classes on the weekends. All the SCI patients thought they had a lot of spare time, and to avoid becoming bored, they searched for ways to occupy this time. They killed time by participating in unstructured activities:

> From the time I finish my classes to the time I go to bed is just time I have to kill. So I usually spend it, I just wheel around the halls and visit or stay up for as long as I can, then lay down.

> Any time I don't have anything in particular to do, which is most of the time in here, is my time to kill. I sometimes go out for supper or play cards with some of the other patients.

> During the day I'm busy working out on my physio and occupational therapy exercises. In the evenings and especially on the weekends is when most of us have a lot of time to kill and are bored doing it. We don't know what to do with ourselves. I try to amuse myself sometimes when I have nothing to do, but the amount of free time we have on our hands here is a lot.

The patients killed time in five areas on the unit: the sunroom, the nurses station, the smokeroom, the roof, and the tunnel.

The Sunroom

In the sunroom, SCI patients watched T.V., rented movies, visited with their friends and relatives, played cards and board games, read books and magazines, listened to the radio, socialized with each other, and held parties. Every week a volunteer brought in rented movies for the patients to see during the evenings. The SCI patients referred to the sunroom as the "visitor's room" because they escorted their guests to this place when they came to visit. When socializing with their family members and friends, they sometimes played cards or board games. In the sunroom, the patients read books and magazines and played the stereo system. SCI patients would come into this room to talk with each other and to participate in social activities, such as, farewell and birthday parties. When the patients spoke about them killing time in the sunroom they said,

> Most of the patients go to the sunroom to watch T.V. or visit with the family when they come.
>
> Sometimes the stereo is so loud from that place, you can hear it all the way to the nursing station.
>
> That's the visiting room. When guests arrive, I take them there. Sometimes we have birthday or farewell parties in that room.

The Nurses Station

SCI patients who killed time by the nurses station watched T.V., ate their evening snacks, and spent time speaking with whoever happened to be in this vicinity, such as, the staff, their family members and friends, former SCI patients who came in for therapy as outpatients, patients from other units, and strangers. Generally, patients who watched T.V. in this location had the television tuned to sports events. In the evenings, a food cart was brought around by a staff member who worked in the dietary department. Some patients ate evening snacks from this food cart while watching the people around the nursing station and the television that was situated in the alcove of the unit. About killing time at the nursing station, patients said,

> I wheel myself up and down the halls or go up to the roof to get some exercise or else I watch T.V. at the nursing station. Most of the time I'm watching a lot of T.V. there.
>
> There are three T.Vs on the unit. One is in the sunroom. That T.V. is usually tuned to movies. That's where I go to watch T.V. One is near the nursing station. That T.V. is always tuned to sports, and one is in the smokeroom. I don't know what that T.V. is doing because I don't smoke and never go into that room.
>
> Most of the patients that don't stick to their rooms come and hang around the nursing station. We sit around and visit with whoever is there.
>
> I eat my evening snack at the nurses' station from the food cart that comes around here every day.

The Smokeroom

When patients were killing time in the smokeroom, they usually smoked cigarettes, watched T.V., and socialized with patients from other units and visitors. Patients who did not smoke generally avoided coming into this room. SCI patients usually watched movies on the television in the smokeroom. When discussing killing time in the smokeroom, patients said,

> I don't go down that hallway because I don't smoke. Who knows what they do in the room where people smoke.
>
> If it's a nice day sometimes I go for a stroll in the chair outside; otherwise, I spend most of my free time in the smokeroom because I smoke or else I hang around the nursing station and watch television.
>
> I like to lay down on my bed once in a while if I don't have anything to do. Sometimes I go to the smokeroom to smoke.

The Roof

There was an area on the sixth floor of the building people on the unit called "the roof." Patients who killed time on the roof came to this place to get away from the unit and for a change in scenery. Windows permitted views of some parts of the city. SCI patients came to this area to get a glimpse of the activities of the outside world. At night

they were also able to see stars and city lights from the roof. When patients described their activity on the roof they said,

> I go to the roof when I want to get away from everything. You can see the city because there are windows up there. It's interesting to watch the people go by when you're looking down at them.
>
> For something different to do, I go to the roof.
>
> When things are kind of slow around here in the evenings, I'll go to the roof and check out to see if I can see the Big Dipper.

The Tunnel

Sometimes patients killed time by doing wheelchair trials in an area in the basement they called "the tunnel." Patients who participated in this activity would time themselves by using a stop watch or they would have races. When asked why they went to the tunnel, SCI patients said,

> They got a tunnel in the basement. It's a big long hall. Mainly it's just for wheeling. There's a slope you have to go up or down on depending on which end you start from.
>
> I go to the tunnel to practice my wheeling. But you know some of them go down there and time themselves to see how fast they can go; others, have races down there.

Lights Out

Most of the patients went to sleep at 2300 hours. After the lights in the hallways and patient rooms were turned off, few people used these hallways. Generally, a staff member who worked in the housekeeping department was usually in the west wing, a few patients went to the smoke room to have a cigarette or watched T.V. by the nursing station for short periods if they could not sleep, and the radios and other television sets were turned off by the staff. In contrast, during the week in the daytime and evenings, there was a sense of business on the unit, with many patients, staff and family members going to and from other departments, as well as, some staff members pushed food, supply, and

cleaning carts in these hallways. Also, music could be heard and all the television sets were on.

Patients who had difficulty moving were turned every two to four hours by the night staff to prevent skin breakdown. Initially, the patients said that they usually woke up when this was done; however, as their stay increased, they generally slept through these turns. Over time, the patients got used to the night routine if they needed to change positions in bed and became relaxed when the staff performed this activity:

> Most of the guys get turned every two hours if they are a new patient, and as your skin toughens, you eventually get turned every four. Some patients don't get turned at all because they can do it themselves.
>
> I'll watch T.V. until about 10:30 and they turn me in my bed because my shoulder is sore. So I lay on my shoulder for an hour then I spend the rest of the night on by back. They don't turn me at any other time like they do other patients.
>
> After I get to sleep they come and roll me over every once in a while. I got now so I don't even know when they come. You know, I just sleep right through it when they flip me over.

Some SCI patients requested no one enter their rooms at night so they would not be disturbed. The staff felt uncomfortable with these requests because they felt obligated to regularly check the patients during their rounds to establish if they were well; therefore, they aimed their flashlights towards the floor, looked at the patients from a distance, and shut the doors to these rooms. The patients respected staff members who were flexible in their routines, who treated them as adults, and were the employees whom they perceived to be genuinely caring. The patient-staff relationships in these situations promoted self-disclosure to take place and, consequently, facilitated the patient's progress during rehabilitation.

V. FINDINGS: FROM ADMISSION TO DISCHARGE

This chapter contains data about the practices and beliefs surrounding a person with a SCI from the time of the incident to the time the patients were discharged from the SCI unit. This data was obtained from SCI patients, their family members and friends, and staff members situated on the unit. The major findings included in this chapter are recollections of the incident, the emergency room, intensive care, and the ward, arriving at the SCI unit, the loss, living with the equipment, the patients use of language, "good" days and "bad" days, the modification of hope, and, finally preparation for leaving the SCI unit.

Recollections

The Incident

Most of the SCI patients in this study could recall details of their accident. The patients could remember the date and general time of the incident, who was present, and factors contributing to their accident. All the patients said that the accident was unexpected. After the patients were stabilized by the trained medical personnel who intervened with emergency care, such as, the paramedics, emergency medical technicians, and ambulance drivers, they were transported to emergency departments of nearby hospitals. Most of the SCI patients could not remember events following the accident from admission to health care facilities or once they were in intensive care. This period of time was usually reported to them by the medical personnel who arrived at the scene of the accident.

When some of the SCI patients recalled details about their accident they said,

> We were driving down the road doing about 60 miles an hour. My girlfriend was driving; I was a passenger. She had her seatbelt on; I didn't. And the front tire blew on the car. When it blew up, it pulled the car into the ditch. I struck my head on the windshield and felt my neck break.

> So my neck hit the bucket seat and snapped backwards a little bit more. Eventually I told my girlfriend to get out of the car. When I tried to get out my legs wouldn't work so I knew I was paralyzed and that was about it until the ambulance came. Once the ambulance drivers came, I went black.
>
> We were water skiing, and we put the boat in the water, and I was standing on the dock, and a friend of mine was in the water. He motioned that I was going to dive in, and he said "I dare you." So I went and I dove off and hit a rock and broke my neck and split my head wide open. It felt like something slapping me in the face, which turned out to be my arms. I went to lift myself out of the water, and I couldn't, my legs wouldn't work. I started to panic, and my friend grabbed me around the shoulders and carried me to the beach, and there was a doctor and nurse already there. They stabilized me until the ambulance came. I remembered everything that happened that day but very little about the emergency department.

The Emergency Room

As many of the SCI patients were unconscious when they arrived at the emergency department, they could not remember many details of this part of their experience. Those who were conscious could remember doctors and nurses giving them medications, applying bandages to their open wounds, and initiating intravenous therapy. Some patients remembered consenting to treatments and experiencing a lot of pain. As soon as the emergency physicians had the SCI patients in stable condition, they were either taken to the operating room for surgery or were transferred to a neuro-intensive care unit.

Recalling details of the emergency room, some of the SCI patients said,

> When I got there, they put me onto an examining table and started an I.V. on me. I was in a lot of pain at that point, and I kept asking the doctors or nurses to give me something. After they checked me for brain damage and feeling of my body, to see what I could move and what I couldn't, then things got pretty hazy from then on.
>
> I remember waking on and off during the ambulance ride, and then I was in the hospital. I was aware of what was going on. I kept asking them to give me something for the pain because it was so bad at times I had to cry. And the doctor said, "We'd like to give you a trachea. It will give

> you a better chance to live." I said it was O.K. Everything was happening so fast. I couldn't believe this was even happening to me.

Intensive Care

Although a stable spine and a stable medical condition signalled a patient's ability to participate in an active rehabilitation program, appropriate management of the SCI patients with an acute spinal cord lesion was part of the process. Prevention of neurological deterioration and other complications, as well as, maintenance of the integrity of functioning systems constituted a major component of a SCI patient's stay in intensive care. Collaborative teamwork among those caring for these patients while in intensive care facilitated their overall progress to an active rehabilitation program. Early consultation with physical and occupational therapists, social workers, and psychiatrists assisted preparing SCI patients for the postacute phase of their rehabilitation.

Although immobilization, the administration of medications, and further stabilization of the spine were important measures in the early management of SCI patients, most of the patients could not remember much of their experiences in intensive care. They felt that the medications given to them masked the reality of their predicament. In addition to the drugs, the sudden accident and the immediate health care interventions they required overwhelmed them. Also, it was difficult for them to believe their accident had actually occurred. Many of the SCI patients said that it was "like a bad dream" and they "didn't really know what was going on." After their stay in intensive care, SCI patients were usually transferred to a neurosurgical ward.

When the SCI patients discussed their experiences in intensive care they said,

> I was conscious of where I was again. But the worst thing about being in I.C.U. (intensive care unit) was a lot of the times you'll wake up and it doesn't click in right away where you are. For a few seconds it's like you wake up and you try and get out of bed or think it's time to go to work. And then all of a sudden you realize again, it's not a bad dream. It happened.

> I had a lot of nightmares in intensive care. For example, every four hours the staff would pound on my chest to clean it out. So lots of times they got on the bed to do this. At times I saw the curtains pulled around the other patients when this was done. I saw these shadows and thought they were trying to kill people here, or I saw these shadows of people jumping on top of the other person and thought they were hookers. I was drugged up quite a bit when I was in there.

The Ward

On-going rehabilitation on the wards included the assessment of SCI patients' physiological, psychological, respiratory, and gastrointestinal status, neurological deficits, body alignment, joint motion, nutritional needs, and bowel control. As it became evident that the patient would survive, SCI patients were introduced to the idea that a productive and meaningful life could be achieved, even though the process involved time, patience, and determination.

All the SCI patients wanted to know if they would walk again. Although their physicians told them about the extensiveness of their injuries and they also heard this information from other sources, such as, the nursing staff, the SCI patients did not believe these people. They were in a state of disbelief and wondered if what they heard was really true. Following their acute phase of recovery, all the SCI patients were transferred to the SCI rehabilitation unit.

The patients began to feel better, and they experienced improved health on the neurosurgical wards:

> The reason I went to the ward after intensive care was if anything happened, they could wheel me back to intensive care. I got in better shape on the ward because I started to get my strength back.

> It wasn't until I got to the ward that I started to feel like I was recovering. I started to do little things, like feed myself, wash my face, and brush my teeth. I couldn't do any of these things in intensive care.

> One day I woke up when I was sitting up on the commode to get my hair washed. I got stronger on the ward and at least I started to do some things for myself.

Arriving At The SCI Unit

Transfer of the SCI patients from the acute care setting to the rehabilitation unit created some anxiety in the patients and their relatives. In addition to the usual fears associated with moving into an unfamiliar environment, meeting new people, and having to learn new "routines," patients faced the unpredictable course of recovery. To allay some of their anxiety and associated fears, the staff explained to the new SCI patients and their family members the routines of the SCI unit. They were told about rehabilitation classes, how family members could reach the patients by telephone, the times and location of meals, visiting hours, policies on drug and alcohol use or abuse, and the use of the laundry facilities. At the time of admission, the staff gave the patients and their relatives a tour of the unit.

As most of the SCI patients had not been hospitalized prior to the accident, they usually spent the first few weeks on the rehabilitation unit becoming accustomed to their surroundings. When some of the patients spoke about their arrival on the unit they said,

> I'd never been in a hospital before, never been in a bed longer than a day. At the beginning, my main concerns were to work hard, to get more movement back, and to get stronger. I was really scared because this was a new place and I didn't know what to expect.

> I had an orientation when I first came here. I didn't know what was coming up next. I found it quite a challenge to get acquainted with a new environment, new people, and new routines. It was quite different going from a new hospital to an old building like this one. I had trouble adjusting, like I got into mood swings, yelled at people, and took my frustrations out on some of my family members.

The patients had ambivalent feelings about their arrival on the SCI unit. Initially, they were scared because they were unfamiliar with the setting and the people, had to establish new acquaintances and routines, and had to learn to overcome, compensate, and adjust so that they could reach their potential. In spite of their fears about arriving on the unit, they also were happy because they felt that their involvement in the rehabilitation

program provided them with an opportunity to walk again, to learn necessary skills, to function independently, and to be integrated back into the mainstream of society.

Staff members recognized that the SCI patients required time to adjust to their surroundings. Some of the strategies they employed to reduce patient fears during this time included answering call bells promptly, spending time with them, encouraging them to ask questions, giving them freedom to make choices (e.g., about the scheduling of classes, food preferences, wearing certain equipment, and the days for tub baths), and encouraging them to voice their opinions. If a particular patient and primary nurse did not develop a rapport, experienced a personality conflict, and felt that they could not work together, the unit supervisor would be notified, and the patient would be given the opportunity to select another nurse.

Some people described the patients when they first arrived to the unit. Staff, friends of the SCI patient's, and family members said,

> Nurse: When they first come, they usually are on their call bell a lot because they are scared about being here and not knowing what to expect. I try and alleviate some of these fears by spending more time with them when they first come. I think some of the little things we could do as staff members have been overlooked.

> Orderly Attendant: When they first come they're fearful, scared, apprehensive about their surroundings. The uncertainty is great, and they're on the call bell a lot. On an average, it takes about two to three weeks, then they start talking more and voicing their opinions. Some people take a longer or shorter time to adjust to this place. When they are comfortable with being here, they stop ringing the call bell, they start to talk more, they wheel around with more confidence, and they start to socialize more with the other patients.

> Occupational Therapist: Usually they're a little bit taken aback. It's like walking into a new network, and you're the new person on the block. So what I like to do is explain what I do and what I have to offer them. Then I ask

them if they have any questions, and usually they don't know what to say, so you casually assess them and start joking around with them to ease the tension. When the patients become comfortable with the place, they ask more questions, stop me in the hallway and talk, or ask me to do something; whereas, before they didn't ask you to help them.

Girlfriend: When my boyfriend came here he was really uptight. He kept looking around the place wondering what was next. It took him about a week before he knew his way around and was familiar with where to go. The other thing I noticed was he started to ask more questions and made some decisions about the help he got from staff. At the beginning, he did what they said, but as he got used to the place, he started to take over and be more in control of his situation.

Father: At first my son was really quiet. As he was in here longer, he started to ask more questions about what equipment would be best, when he could go on weekend passes, what can he expect in the future, and things like that. As parents, we started to ask more questions too because we knew that by my son being here was a stepping stone to him coming home.

Strategies used by the staff during the SCI patients' arrival to the unit and rehabilitation were teaching, encouraging problem solving, listening, and mutually setting patient goals. Teaching included any activity that provided the SCI patient with information needed to prevent or reduce stress, to recognize and use resources, and to develop new behaviors. By asking questions, making suggestions, reminding the patients of alternatives or resources, staff members encouraged the SCI patients to participate in problem solving activities. This communication process helped the patients become more committed to the decisions they made. It helped the staff to act on and revise decisions concerned with patients' goals and made them more attentive to patients' concerns and input. Once the SCI patients became accustomed to the unit and participated in the rehabilitation classes, they acknowledged their loss of ability. Some of the patients said,

After awhile I realized that my limitations may be permanent. You always hope you will get back as much

> as you can, but I knew after about six weeks of being here that this is the way it was.
>
> You know that you can't do a lot of things after awhile, but you never give up. I know what my limitations are, but that doesn't mean you can't hope for more.

The Loss

As a result of the traumatic disruption and loss of body function caused by their accident, the SCI patients said that they experienced emotional distress. According to the patients, this distress included dulled and slowed intellectual abilities, poor emotional control, and withdrawal. At first, SCI patients did not fully comprehend their predicament and showed little interest in their surroundings. As the SCI patients were stabilized in the intensive care unit and the "step down" neurosurgical wards, awareness of their circumstances became heightened, and they gradually became interested in their surroundings. During this period, SCI patients were aware of their inability to perform activities; consequently, they welcomed assistance from the staff.

The acute care facilities provided physical and psychological stability for the patients, and they became certain that everything would "turn out alright." The patients believed that the care they received, during the acute care phase of rehabilitation, would promote the return of their predicament to preaccident normalcy. Unfortunately, when they were transferred to the SCI rehabilitation unit, SCI patients were confronted with experiences that shook their belief of recovery. For example, new SCI patients observed other patients engaging in physical therapy without experiencing full recovery, and they began to realize the potential permanency of their own injuries. All the SCI patients, their friends, staff, and family members said that the consequence of a spine injury involved a loss:

> Patient: I lost all sensation from my bellybutton down. My strength is not what it used to be. I have to do things different now because of my injury. It was a tremendous blow to me when things changed so suddenly.

Friend: My friend has gone through an awful lot. Things just happened so fast. The loss is great. I don't know what I would do in his situation. Not being able to do things that you used to take for granted is a lot of change in your life.

Staff Member: All the patients experience a loss. They can't do things the way they used to. Everything changes for them.

Mother: The accident happened so suddenly. Now my son is faced with having to change the way he does things. The loss is too great to bear. I wish it was me instead of him. I'd do anything to make things the way they used to be.

Father: My son is always looking for something new to try. He can walk, but it's not functional walking because he has to put full weight on his right leg. Things will never be the same now. No one knows what it's like to go through a loss like this unless you experience it yourself.

The onset of the spine injury was sudden, unexpected, and overwhelming to the SCI patients and their relatives; they could hardly believe their predicament to be true. One of the most devastating consequences of the accident was its effect on the patients' body image. The SCI patient's perception of his or her body, its size, functions, and potential changed during the process of recovery. Body image was unique to each patient; however, certain parts of the body were valued more than others by the SCI patients. For example, all the SCI patients felt that their inability to walk made them less of a person:

> I used to be very active in sports. Now that I don't have use of my legs, it changes how I feel about myself as a person. Most of the guys here feel that they have less to offer because their legs don't work.
>
> It's like having your life fall apart in front of you, watching it crumble. There's nothing you can do about it, yet you experience so many changes with your body. I used to have really thick thighs. Now they are just like rubber hoses. I'll never be the same.

Not being able to control situations, such as, having a bowel movement or having spasms, frustrated the SCI patients. It took time for the patients to realize that impairment

did not involve total disaster and a wasted life. Eventually, SCI patients realized that an imperfect body did not affect their identity. The rehabilitation process involved developing self-confidence to cope with the changes. SCI patients had to learn to move in space, to become aware of a new body image and sense of self, to accept the possibility of never being able to resume certain roles, and to reassess their previous priorities and values. SCI patients felt that there was a long, hard journey ahead of them, and they were afraid to face the possibility that they would never walk again as they once knew they could. Attempts by the SCI patients to deal with and compensate for their physical losses involved the use of a variety of equipment.

Living With The Equipment

Due to the impairment of sensation and movement caused by a spine injury, SCI patients used equipment to achieve independence. This equipment included the clamshell, a wheelchair, a leg bag, and a halo traction. This equipment was used by the SCI patients to assist, facilitate, support, and replace functions unobtainable by other means. Although the use of some of this equipment distressed the SCI patients, they used this equipment to gain additional independence. SCI patients' equipment was individualized, and the use of this equipment involved trial and error to manage their predicament. Although their patience was frequently tested, the patients knew that failure often preceded success.

The Clamshell

Some of the SCI patients wore a piece of equipment they called a "clamshell." This equipment was usually made of plastic, had a front and back shell with velcro straps that were placed on the patient's torso, and provided limited movement of the spine. Most patients who wore a clamshell found it to be restrictive when they moved. Some of the patients said that wearing the clamshell caused them pain in the groin area if the length of it was too long and they required time to get used to wearing this piece of equipment.

Also, patients said that they had difficulty when voiding in the toilet if they had the clamshell on as they felt this piece of equipment obstructed their view.

SCI patients only wanted to use a clamshell on a temporary basis. They did not feel that wearing this equipment improved their looks. Generally, the patients were embarrassed when they wore a clamshell, and they looked forward to the day when they could remove it. Strategies staff employed to relieve some of the discomfort patients felt when they wore a clamshell included conducting frequent checks to ensure the size and length of the clamshell were appropriate, making necessary adjustments to the equipment, implementing regular cleaning routines, and providing instructions to patients about a skin care program.

Some of the SCI patients spoke about their experience with having to wear a clamshell and said,

> It's what they use instead of a body cast. It's just like a two piece shell that they clamp on to hold your spine in place while it heals. I found it hard to get used to at first, but eventdally it becomes second nature to have it on because you get used to it. At least with this thing on you can cover it up with a shirt if it's big enough.
>
> It's not easy wearing this clamshell. Sometimes it presses against your groin if you lean over too much or position yourself too quickly. These darn straps are too short. Sometimes they come undone depending on how I move with this on.
>
> Usually I can't sit right with this thing on. It sometimes stops me from hitting the toilet when I go to the bathroom because you can't see over it that well. It is really uncomfortable to wear. You perspire more, and it get's itchy underneath.

The Wheelchair

A wheelchair provided self-mobilization for the SCI patients when ambulation was not feasible. The use of a wheelchair as a primary mode of transportation required educating patients about the management and use of the wheelchair, accessory parts, and obstacles in all types of environments beyond the SCI unit. Experimenting with the

wheelchair in certain situations, such as, curbs, doorways, corridors, shopping malls, and movie theaters, was considered part of their rehabilitation program. These activities were intended to provide the patients with opportunities to problem solve. The SCI patients said that having these test runs during their rehabilitation program prepared them to manage awkward and difficult locations when they were out on passes or after their discharge. Upon discharge, most of the patients said that they felt comfortable and were confident about using a wheelchair.

The SCI patients reported that they felt like second class citizens when they were in their wheelchairs. They recognized the necessity of using a wheelchair; however, all the SCI patients worked hard to overcome their limitations and hoped that they would, someday, be able to stop using this equipment. They wanted to be normal and felt that being in a wheelchair restricted their opportunities in life, such as, acquiring a job or attending certain social functions:

> I don't accept the fact that I'm in the chair because in today's society everything revolves around being beautiful and being in shape. Being in a wheelchair doesn't reflect any of these things. When you're in the wheelchair, people are curious, and they look at you; or when you're being pushed by someone else, they sometimes forget that you are there and start to talk to someone while my back is to them. That really bothers me. You are excluded, and you can't see what's going on. Being in the chair also influences what places you can go to.
>
> When you're in the chair, people talk down to you as if you are a child. You have to constantly prove to people that you have a brain or else they think you're helpless. It's like being a second class citizen.
>
> It's hard work. People think just because you're sitting down in the chair you're not working—well I'm working 24 hours even when I'm in my chair wheeling around. It sure is a humbling experience. The house had to be changed for the chair, a vehicle had to be bought for the chair, and places I go depend on the chair. It's like your whole life depends on this damn chair.

All the SCI patients resented the fact they had to use wheelchairs for transportation. At first, the patients said that it was a novelty for to them to wheel around and socialize with other patients and staff members. In the beginning, they felt comfortable and felt they were accepted by these individuals; however, in time they realized the potential permanency of their injuries and possibility of having to use a wheelchair for the rest of their life. This depressing perception was compounded by the realization that, beyond the SCI unit, they felt that they were considered to be different from other people because they used a wheelchair. The patients said that it was a lot easier to introduce themselves to other patients because they believed that these individuals were going through similar experiences and would be more understanding and empathetic than outsiders.

When SCI patients socialized with "abled" persons, they said that they had to look up to establish eye contact. This frustrated the SCI patients because they felt that this position placed them in an inferior social position. For example, patients said that when they were in a shopping mall, people offered to help them with a door, to make a purchase, or to position them behind a table at a restaurant. Usually, the SCI patient did not want this help, nor did they want pity from these individuals. Although the wheelchair assisted the patients with their mobility, being labelled an individual in need of help was considered a negative consequence by the SCI patients.

Leg Bag

Some SCI patients' bladder management program involved reflex voiding. In order to decrease the possibility of urinary incontinence, these patients used an external collecting piece of equipment they referred to as a "leg bag." Female patients had indwelling catheters connected to this leg bag, and male patients wore condoms that were attached to this equipment. Initially, the patients who wore leg bags felt that they were a means to gain control of embarrassing situations, such as, voiding in public, considering

the lack of control of their bladders, in these circumstances, was one of the SCI patients' greatest fears. The patients said that the self-disgust, shame, and frustration brought about by these embarrassing situations depressed them.

Usually, patients who wore leg bags had this piece of equipment on when they were leaving the unit with family and friends. All these patients tried to conceal this fact when they were in public. The patients said that they felt embarrassed about wearing the leg bags because they found this equipment to be unattractive. Also, the patients said that wearing the leg bags affected their body image. Although these patients said that they tolerated wearing this equipment, they never got used to it.

During the tape recorded interviews, some of the SCI patients commented on the experience of wearing a leg bag and said,

> It takes some time to feel comfortable with it on. The bags are made of plastic, so sometimes when it's hot outside, the plastic sticks to your skin. I never wear my leg bag with shorts. It's just too embarrassing.

> You have to remember to empty the bag, hope that it never leaks when you're out, and be careful about knocking it against something sharp. There is nothing worse than having one of these bags explode, with urine all over you, when someone else is around. That is so degrading.

> I don't like to have something wrapped around my leg, but what choice do I have if I want to avoid a mess. I want to be able to sit around in shorts, but how attractive is that to the opposite sex? You feel self-conscious about wearing it, so I always wear pants when I have my leg bag on.

Halo Traction

Regardless of the level of injury, closed or external alignment of the spine was generally initiated in the acute stage of rehabilitation for the SCI patients. Most often, this entailed the use of various types of "skull tongs" and "halo traction" to align the vertebral column and relieve pressure on the neural tissue. Most of the patients were first placed in skull tongs and then were measured for a piece of equipment, formed like a jacket, that would permit them to sit upright in a wheelchair. Some of the patients arrived at the SCI

unit in halo traction. Generally, these patients described the features of this equipment and commented on what it was like to wear it:

> It's a totally different feeling when it first came off because my head would just go where it wanted to. When I had it on, I had to turn my shoulders in order to see in that direction because I couldn't turn my head with the halo on. I had to build strength in my neck, to control where I wanted my head to go, once it came off.

> I had a different balance with the halo. Once the thing came off, I had to relearn my balance. It has a jacket with sheep skin lining and this metal ring around your head. The rest of the attachments connect the jacket to the metal ring around your head to keep you from moving your neck when it was healing.

> I think a lot of my anger that I had when I got here was because of that contraption that was stuck to my head. Since I got my halo off a lot of people have noticed that I've been in better moods. I think I was mad because of the restrictions the halo had on my life.

Similarly to the situation of using a wheelchair or wearing a leg bag, the SCI patients in halo traction felt that they were "on display" when individuals stared at them. The patients said that the reactions they received from people that could walk influenced the development of their self-worth and body image. Stereotypic beliefs held by abled individuals, such as, providing help when help was not requested, had an adverse effect on the SCI patients' well-being. One of the major problems faced by the SCI patients was other people's perceptions of them. SCI patients said that they wished to expand their horizons in various directions; however, they were discouraged from doing so because of society's assumption that they were incapable of achieving similar goals in life compareable to able persons.

The Use Of Language

The language of the SCI patients included much swearing words, and some of these words were printed on T-shirts, and were frequently worn. The context of their swearing was unlike people who swear, for example, in men's locker rooms, pubs, or

gambling casinos, but constituted behavioral responses to their predicament. Swearing had four basic functions for the SCI patients: it served to maintain personal space, to maintain the comradery of the group, to release emotions, and to build facades.

Maintaining Personal Space

For SCI patients, swearing helped to maintain their personal space. The SCI patients referred to their personal space as "breathing room," that area with invisible boundaries that surrounded their bodies while being hospitalized. Personal space was difficult for the patients to maintain as they interacted with a number of health professionals during the day, such as, the physio and occupational therapists, the medical doctors, the psychologist, the social worker, the recreational therapist, and the nurses. During the evening, the SCI patients spent time with the nursing staff and received visitors. At night, they slept in rooms with each other and were surveyed by the night staff. Consequently, the patients' personal space was constantly tested because they were around people all the time. During tape recorded interviews, the patients commented on their personal space and said,

> Everywhere you go during the day there are people all around. I can't think of any time that I can be alone here unless I choose to go outside. Even then you are hard pressed to have some thinking time to yourself, and be able to breath.
>
> If I need some space, I go to my room and shut the curtains around my bed. This way, there isn't someone hanging around me all the time.
>
> Before my accident, I used to spend quite a bit of time by myself. And then there were times when I enjoyed going out with people. But here is a different matter. You are forced into a situation where there are people around you all the time. It takes getting used to. If someone crowds my space, I just tell them to back off.

Throughout their rehabilitation, SCI patients found maintaining their personal space a trial. SCI patients constantly had to prove things to others. They had to prove to the health team members that they had achieved a level of independent functioning prior

to being discharged. They had to prove to family members that they were ready to come home or were able to live somewhere else. They had to prove to their friends that they could maintain their friendships, and to strangers, they had to prove that they were people. SCI patients protected their personal space by swearing in two ways: by wearing T-shirts that had coarse messages written on them, such as, "Fuck you" and "What the fuck are you looking at" or by telling people to "Fuck off," "Bugger off," or "Go to hell."

The SCI patients who wore these T-shirts said that it was their way of letting people know they were not to be pushed around like robots. For example, some of the patients said,

> I wear these T-shirts because I'm sick and tired of being pushed around and having to live with the rules in this fuckin place. You're suppose to be up by seven-thirty during the week and are expected to be in bed by eleven. For the most part, the nursing staff is really good. But they need to be more flexible about things like what time you have to be up, what time you go to sleep, what time visitors have to leave, and what day you have to be back from weekend passes. We are the ones that have to live here twenty-four hours a day. If they took these things into consideration, it would be a lot better and make a person feel like a human being than some goddamn robot.

> I have three T-shirts that have swear words on them. I wear them to be understood. This way people take notice. It's a way of telling them not to mess with me and push me around just because I'm in the chair. If the T-shirt doesn't work, then I tell them to "Fuck off" right to their face.

> Just because my legs don't work doesn't mean that my brain isn't functioning. People don't realize that my back is broken, nothing else.

When the health team members intervened with health care activities for the SCI patients, such as, doing their catheterizations, administering their rectal suppositories, giving them a tip in their wheelchairs when they became dizzy, or teaching them how to dress, the patients tolerated the staff entering their personal space because they felt that these activities were essential to their well-being. The patients said that it was important

for the staff members to perform health measures that would promote their health and tolerated the "invasion of their privacy" when some of these activites were implemented during their stay on the unit.

On occasion, personality conflicts developed between the staff and the patients. When these situations arose, both parties recognized their need for personal space and felt that it was better to stay out of "each other's hair." Otherwise, only the people the patients trusted were allowed to cross into this spatial territory. Strangers or persons they disliked were not permitted to gain access into their personal space. For example, if one SCI patient developed a close relationship with another SCI patient, they would position themselves next to one another while they watched T.V., tell jokes to each other, play with the brakes on each other's wheelchairs, lock arms at the elbows when they went by each other, or try to scare one another by bumping into the back of their wheelchairs. If a stranger attempted these activities with the patients, he or she would be rejected by them because strangers had not developed an interpersonal relationship with the patients; consequently, SCI patients wanted to maintain a distance from these individuals.

The swear words SCI patients spoke when their personal space was jeopardized by others were meant as insults. When they said to someone "Go fuck a duck," they wanted the individual to leave. The most common words spoken in these situations were "fuck you," "you motherfucker," "you fartsucker," "you prick," "you bastard," "go to hell," "fuck off," "bugger off," "screw off," "piss off," "asshole," and "dink."

The intent of swearing, by the SCI patients, was polite in situations where people were invited to get closer to them, such as, a staff member they had developed a good rapport with, a person they were attracted to, or the friendships that developed amongst themselves. Phrase words spoken by the patients in these situations included "How the hell are you?," "Oh for Christ sake!," "Oh piss!," "getting some," and "old man." For example, a patient was in the sunroom watching television. He said that he was

expecting a friend he had not seen in a long time to come and visit in the evening. This is part of the conversation that ensued when this visitor arrived:

> P: How the hell are you?
> V: Fine, how the hell are you?
> P: Not to bad. It's the same old stuff. Sure is nice to see ya. Anything exciting happened since I last saw you?
> V: Not a hell of a lot. I got a job as a legal secretary, and it seems to be working out alright.
> P: What the fuck is Randy up to?
> V: Well, he still drives a gravel truck for the same company, and he is getting married this March.
> P: Oh, for Christ sake!

Maintaining the Comradery of the Group

For the patients, swearing also served to maintained their group identity. SCI patients stuck together. They hung around with each other, they looked to each other for support, they communicated different information to each other than they did to their friends, staff, and family members, and they spoke about each other having similar characteristics. Examples of what the SCI patients said about having similar features included:

> We stick together because no one knows what it is really like to have a broken back unless you have gone through the same thing. It's the same thing with the chair. No one else really knows what it's like to be in a wheelchair but the person that has to. Sure someone that can walk can sit in the chair and wheel around in it for a day or two, but they really don't know what it's like to have to use the chair if you don't have any other choices.

> The people that I feel close to in here are the other patients. They know what I'm going through because they're also going through the same thing.

All the SCI patients said that they perceived themselves to be different from healthy people. For example, there were four patients who occupied the orthopedic beds on this unit. Each of these patients had parts of one or more of their limbs amputated prior to their arrival at the unit. When the SCI patients were asked if they

considered themselves to be the same or different from the orthopedic patients they said there was no difference. The SCI patients said,

> There is no difference between Martha and myself. She has to learn how to manage being at home just like I do.

> The people here that have their legs cut off is no different than me. I might as well of had mine cut off too because they don't work worth a damn. So what's the difference. Any people that have to deal with problems with their health also have to learn to handle it.

The similar circumstances of the SCI patients brought them closer together. They associated with each other and were a cohesive group. The comradeship between the patients was strong. They tried to cover up for each other, gave praise to one another, shared secrets, and spoke about their feelings when they were with their SCI peers.

Swearing was considered to be an acceptable form of behavior in the SCI group. Their swearing served a social purpose because no other groups on the unit spoke coarse language in the same context as their group did. The other groups consisted of their friends, staff, and family members. Swearing by the patients had to be learned by newcomers if they were to be part of this group. The patients' swearing was a device which controlled who belonged to their group and who they perceived to belong to other groups. Swearing by the SCI patients distinguished them from other people who swore and served to maintain their group identity.

The SCI patients' swearing increased over time, and patients that came in and were nonswearers swore by the time they left the unit. The SCI patients talked about these changes during interviews:

> I never swore so much until I came here.

> Since I've been in this place, I swear more and watch a hell of a lot of T.V. It even changes. The longer we stay here, the more we swear.

Although swearing divided the SCI patient group into subgroups, there was no difference between the male or female SCI patients potential for swearing. Both genders swore when they were in the same situations. For example, some of the patients were positioned in front of the T.V. by the nursing station. One male patient was holding a styrofoam cup with coffee in it and happened to spill some of the coffee onto his lap. The first words that came out of his mouth were "Son of a bitch." Two days later, one of the female patients was having lunch in the cafeteria on the fourth floor of the building and also happened to spill some coffee that she was drinking onto her lap. She bent her head down and said "Jesus Christ. Wouldn't you know it." Differences in swearing by the SCI patients were related to the age groups that they belonged to. The younger patients (those aged approximately from 17 to 35 years-of-age) swore more than the middle-aged patients (those between 35 and 60 years-of-age). Further, the middle-aged patients swore more than the elderly patients (those who were over 60 years-of-age). Also, the younger patients had a broader vocabulary of coarse words compared to the middle and elderly patients (see Table 2). The elderly patients spoke a few choice words like "shit," and "Jesus Christ," but they never said the word "fuck."

The young SCI patient age group swore no matter who was present, and they were the only ones who wore the T-shirts with coarse words on them (see Table 3). This group was not inhibited to "speak their minds" by swearing in the presence of their friends, staff, and family members. For example, the young SCI patients swore no matter which family members were present. The middle-aged SCI patients were more reserved when they swore, particularly if staff and family members were near. They rarely swore when their relatives visited. The elderly SCI patient group swore in personal situations when they became frustrated; otherwise, this group of patients seldom uttered coarse words in the presence of staff, family members, friends, or strangers.

Table 2: *Swear Words Used By Each SCI Age Group*

SCI Groups		
Young (17-35 yrs)	**Middle Aged** (35-60 yrs)	**Elderly** (over 60 yrs)
Fuck	Fuck	
Motherfucker		
Shit	Shit	Shit
Goddamn	Goddamn	
Piss	Piss	
Jesus Christ	Jesus Christ	Jesus Christ
Asshole	Asshole	Asshole
Hell	Hell	Hell
Son of a bitch	Son of a bitch	
Cock	Cock	
Cocksucker		
Bitch	Bitch	Bitch
Screw	Screw	
Jerk	Jerk	
Prick		
Dink	Dink	
Bastard	Bastard	Bastard

Table 3: *Choice Words Spoken in the Presence of Other Groups*

Group	SCI Patients		
	Young	Middle Aged	Elderly
Strangers	Fuck Shit Goddamn Piss Jesus Christ Hell Asshole Bitch Prick Dink Bastard	Nil	Nil
Friends	Fuck Shit Goddamn Jesus Christ Asshole Bitch Prick Dink Bastard Hell	Fuck Shit Goddamn Jesus Christ Asshole Bitch Prick Bastard Hell	 Shit Jesus Christ Asshole Bitch
Family Members	Fuck Shit Goddamn Jesus Christ Asshole Bitch Bastard Hell	Fuck Shit Goddamn Jesus Christ Bastard Hell	 Shit Jesus Christ
Staff Members	Fuck Shit Goddamn Jesus Christ Asshole Bitch Prick Dink Bastard Piss	Fuck Shit Goddamn Jesus Christ Bitch Prick Bastard	 Shit Jesus Christ Bitch Bastard
To Self	Fuck Shit Goddamn Jesus Christ	Fuck Shit Goddamn Jesus Christ	 Shit Jesus Christ

The swear words all three SCI patient age groups choose to speak when other people were around changed with respect to what words were said and the objects of their swearing. For example, when they swore in the presence of family members, they said words such as "shit" and "hell," compared to words, such as, "cock sucker" and "prick" in their patient group. Their objects of swearing in the presence of family members did not pertain to their personal situations, such as, having a bowel accident, spilling some soup, or falling from the wheelchair, but their swearing pertained to family matters, such as, disputing over what changes should be made in the parent's home to increase wheelchair accessibility, discussing marital difficulties, and expressing their dislike for hospital food. The SCI patient age groups also spoke certain swear words when they were with staff members, friends, and strangers. The swear words they spoke when they were with other groups of people and the context of their swearing in these group situations differed from their own patient age groups. Thus, swearing by the different ages of patients helped to maintain the identity of each patient age group.

Releasing Emotions

Swearing for SCI patients also provided a means for releasing emotions. Swearing was used by the patients as an "escape-valve," for letting go of their excess passions. Patient swearing acted as a relief mechanism for their pent-up emotional energies. The emotional energies they formed were permitted to escape from their bodies and brought about the restoration and preservation of the patients' pyschophysical equilibrium. When patients felt excessively happy or sad about a particular event, they became over-energized, placing themselves in a state of imbalance. Swearing brought relief to SCI patients by helping to release their emotional energy until their normal physical and psychological well-being was reestablished. According to the patients, if this energy was not released, there was a potential risk for the development

of future health problems; consequently, swearing promoted the health of SCI patients because it acted as a vent for leaking out these emotional energies. The SCI patients said that they felt "relieved" when they swore during intolerable periods of inner conflict, attempted inhibition, repression, and readjustment. Also, the burdens, as well as, the joys of the patients were eased when they swore. Swearing was tranquilizing and pacifying and produced emotional satisfaction for the SCI patients.

Unexpected situations, such as, moving their fingers and brace walking for the first time, discovering their leg bags were disconnected and urine was draining onto their clothes and the floor, having a flat tire on their wheelchairs when they were eating in a restaurant, and waiting for a late transportation vehicle to arrive, were emotionally stressful experiences for SCI patients. The patients said that swearing helped them let go of their happiness, anger, frustrations, aggressions, and shocks.

SCI patients experienced a sense of relief when they swore, and the stimuli for their swearing depended on the situations. The patients described the release of their emotions as "blowing off steam," and they felt relief when their "tensions" broke. The patients commented on the importance of their emotions being released when they said,

> Sometimes I could just scream, I get so frustrated with not being able to do things. It's not easy living with these restrictions. I get to the point where instead of screaming and bashing my head against the wall, I start to swear like a trooper.
>
> I get so damn mad when I have to wait and have things done for me. It's no wonder I swear because otherwise who knows what I would be capable of if I didn't let these things get out of my system.
>
> There are so many changes. Every change is stressful. The way I deal with the changes is I let things out. There is one guy here who keeps things to himself. I know it's bothering him. If I did that I would be a basket case.

Instead of keeping their feelings inside, SCI patients used swearing as a coping mechanism. SCI patients swore as a response to their jubilations, deprivations, and

frustrations. The verbal assault of swearing served as a substitute for actual physical abuse. Swearing was a civilized form of behavior for the patients, and it replaced their potential for physical violence.

The array of disturbing situations that provoked the SCI patients to swear ranged from minor conditions, such as, not being able to find their comb in their bedside table, to events, such as, having a sudden bowel movement in the middle of the hallway. When faced with the minor episodes, patients usually joked about their predicament and quickly forgot about these situations. The unpredictability of bowel or bladder accidents was one of the SCI patients' greatest fears, and these situations caused them feelings of self-disgust. When these situations arose, patients became angry, lost control of their language, and swore in an explosive manner. Swearing was a reaction by the patients to situations which threatened their self-worth.

Building Facades

Swearing also permitted SCI patients to build facades to prevent self-disclosure during their rehabilitation. The facades they built by swearing protected them from the reality of their overwhelming situations. Most of the SCI patients said that their rehabilitation program did not prepare them for the outside world. Everyone, patients, staff, and family members described their experiences with the rehabilitation program and said,

> Patient: When I started to go out on weekend passes, I realized just how limited I was in doing things. I'm at the point of being discharged and don't know just how well I'll be able to cope. Going through the program really doesn't prepare you for what you have to face.

> Patient: I was discharged a month ago, and it's so different for me out here compared to being in the hospital. I'm only beginning to see who I am as a person since I left. Before that I hadn't even thought about it.

Staff: Most of the patients are not ready to handle the rehab program until sometime after they get discharged. It's just too soon. They have to cope with all these changes, and I'm not so sure how I would handle it if I was in their place. No one knows unless you're in the situation yourself. Sometimes it takes up to five years before the patients are ready to deal with their injury.

Staff: I get calls from patients after they're discharged asking me questions about how to do this or how to do that. Even though we covered it in class, they just weren't ready to deal with these things at the time they were in here. Usually two years after their injury is when they begin to take a realistic approach to things in their life.

Mother: Everything is going fine. My son will be discharged soon and will make the best of his situation because this is always what he has done in the past. Nothings changed except the way that he has to do things now. [Mother begins to cry].

Wife: The most important thing with my husband is we talk to one another. If you didn't have good communication before the accident, the marriage won't last. I try to hug my husband and show him that I still love him, but it's not easy raising the kids, managing the home, and coming here every weekend. We'll do O.K. once he comes home. I won't ball him out for not doing this or that around the home and be strong about this whole thing. [Wife begins to cry].

If the SCI patients revealed how difficult it was for them, they ran the risk of being vulnerable to others' assessments of how well they were coping. The patients feared that other people would think they were not strong enough to take it. They did not want to be criticized for being weak or afraid of the future. At the same time, they were aware that parents, spouses, or friends, particularly if they were girlfriends or boyfriends, were also trying to come to terms with the patients' spine injury. The patients said that they did not want to burden family members because they felt their relatives already had enough to manage. With their friends, the patients did not complain because they wanted their friends to come back. One patient said, "No one wants to hear about your worries all the time." Also, they did not want to be perceived

as "chronic complainers" by the staff. Swearing provided the patients with a means to build fronts so that their actual feelings could be hidden from family, friends, and staff members.

The SCI patients swore to demonstrate endurance and toughness. They wanted to show the world how brave they were, that they would not be a burden to their caregivers, and that they could take it. It was much safer to display a rugged image, an image of managing, than to be depressed, lack enthusiasm, and sit like "a bump on a log," which were their thoughts when they saw no signs of improvement in their ability to move their limbs. SCI patients swore rather than told people they feared being disabled for the rest of their life. Swearing was a means to shelter their inner most self from others.

The SCI patients principally built five facades by swearing. They built facades for friends, family members, the staff, the SCI group, and themselves. Each of these facades served to protect them from disclosing their true feelings to others.

The Friend Facade

SCI patients built a facade for their friends to protect self-disclosure taking place to these individuals about the difficulty of managing their predicament. Their friends included acquaintances, people they had known for some time, and the individuals they were dating. At the beginning of their hospitalization, SCI patients said that their friends came to see them a lot. As their hospitalization continued, their friends' visits decreased to the point of not coming at all. Towards the end of their rehabilitation program, the individuals that remained close friends with the patients kept coming to the unit. The majority of the SCI patients broke up with their girlfriends or boyfriends; whereas, SCI wives or husbands continued their relationships. SCI patients said that this happened because girlfriends or boyfriends could not handle a relationship with someone who had

disabilities: "They didn't want to stick it out." The patients believed that a wife or husband were obligated to their spouse and stayed because it was their duty.

The Family Facade

SCI patients also built facades for their family members to prevent them from revealing their inner most feelings to their relatives. SCI patients who had parents that visited them enjoyed their company. When patients spoke with their parents, they discussed the news from home. They did not discuss how each other was coping because it was too painful for either party to address at this point in time. The parents said that they were afraid of upsetting their son or daughter, and the patients said that they were afraid of making it harder than it already was on their parents. Uncles and aunts spoke with caution to their nephew or niece because they felt that their relative was in "a delicate situation." They were also scared that they might say something that would do them more harm than good. All SCI patients who had parents that came to see them on the unit said that their mother was with them day and night while they were in intensive care, and their mother was the one family member they did not want to burden with their problems. They were close with their fathers, but when something devastating happened to them, such as, when a girlfriend or boyfriend broke up with them, patients said that they first turned to their mothers for moral support. The parents came to visit regularly and their visiting did not decrease during the patients' postacute phase of rehabilitation. The SCI patients who had no parents received encouragement in these situations from close friends and the members in the SCI group.

Husbands and wives faithfully came to visit their spouses; however, they came less often as their spouses' stay on the unit increased. SCI patients who were married said that when their wives or husbands visited it was difficult to have privacy, so they looked forward to weekend passes and used that time to share intimate moments. Husbands and wives said that they talked about their children (if they had any), financial

matters, any new occurrences at home, and the changes in sexual intercourse. Most of the couples said that they seldom discussed how each other was coping with these changes.

The Staff Facade

SCI patients built facades for staff members to hide their true feelings when they spoke with these people about managing their predicament. SCI patients perceived the staff as authority figures who were there to help them. For the first two days after the SCI patients arrived at the unit, they frequently rang their call bell. They wanted reassurance from the staff that they were not too far away if they should need anything. When they called for a nurse, they asked if they could have more blankets, be turned, eat something, or have the thermostat in their rooms turned up or down. If the patients were quadriplegics, they stayed in their beds for several days; whereas, if the patients were paraplegics, they began socializing with others sooner.

After two to seven days, SCI patients began to ask the staff questions about their stay. They wanted to know how long they would be there, whether they would walk again, and how to manage some of their care. SCI patients said that they were afraid of the unknown. They saw the unit as an older building, with less space and facilities, than the hospitals they were in during their acute phase of recovery. The patients described their initial stay as "getting acquainted with their surroundings, the people, and the other patients." There were individual differences with each patient about how long it took to settle in, but all of the SCI patients felt that after one month they were used to the unit's routines. SCI patients who were readmitted to the SCI unit said that they were familiar with the routines, they felt comfortable about arriving on the unit, and they immediately started socializing with others.

In time, the SCI patients developed likes and dislikes towards certain staff members. The staff the patients liked were the employees whom they perceived to be

genuine in the deliverance of their care, treated them like adults, were more relaxed about the rules and regulations, and told them information about themselves, such as, where they lived, what their hobbies were, how many children they had, and where they were going on their holidays. The patient-staff relations in these situations promoted self-disclosure on the part of both parties. Patients told the staff they liked being cared by about their difficulties, disappointments, and frustrations. According to the SCI patients, the staff who developed a rapport with the patients were attentive listeners, did not pass judgements, gave constructive criticism, functioned well as a team member, had a variety of work experience, and gently pushed the patients to be involved in their rehabilitation program when they were "down and out." Although SCI patients felt that favorite staff members were sympathetic, they did not tell these staff their inside fears about being disabled for life. The reason they did not share this information with these people was the patients felt that they were not ready to discuss the permanency of their injury and always hoped for improvements. For example, if a staff member they trusted told them they would have to use the wheelchair to get around, patients did not want to believe this would be the case. They would go and speak to others and check to see if this information was true. Even when patients were obtaining the same answers to their questions, they found this information painful, and they continued to seek out someone who might tell them what they wanted to hear. One SCI patient said,

> No matter how close you are with the staff, you don't want them to know that you think about suicide sometimes, especially, when you can't see anything to live for. These moments pass for me, depending if I'm having a good day or a bad day. If you say anything, they might think that you're loosing it when you just need someone to be living this dream instead of it being you.

Patients disliked staff whom they considered to be rude, bossy, rigid, "were only there for their paycheck," had a superior attitude towards patients, and thought they knew everything. Patients said that these staff made them feel like inadequate human

beings, and they were reluctant to ask such a staff member for help. SCI patients said that they did not reveal anything to the staff they disliked because they felt these individuals did not like them as people to begin with, did not value what they had to say, and considered their input unimportant to them.

There were also staff members who evoked feelings of indifference. Patients felt that these staff had little interest in a patient's rehabilitation program. Patients perceived these staff as strangers and did not disclose to them.

The Group Facade

SCI patients also built facades for their own SCI group to hide their fears about their limitations to their SCI peers. Even though the improvements and setbacks they experienced were shared in this group, each patient was reluctant to "spill everything out." For similar reasons, when patients interacted with friends, family, or staff members, they wanted to project an image of being in control of their situations. They did not want their SCI peers to think that they were weak.

The patients would compare themselves to each other and determine if they were worse or better off than any one of them. This constant comparison between them helped each patient recognize their strengths and weaknesses. Most SCI patients had never been in a similar predicament before and they had to learn the behavioral norms for disabled persons. SCI patients acquired this knowledge from their group. They would watch to see how each other reacted, made mental notes about how to manage circumstances they had never faced from experienced patients, and received tips about managing their day-to-day activities. Experienced patients taught newcomers the "ropes" of being a SCI patient. Despite the groups effort in developing a sense of "We are all in this together," in order to cope with his or her limitations, each patient held back private thoughts and feelings from their SCI peers.

The Self Facade

SCI patients also built facades for themselves to conceal their remorse about sustaining permanent damage to the spine. Having to contend with so many physical, social, and emotional changes involved struggling with activities SCI patients once took for granted, such as, opening containers, buttering a piece of bread, putting on a pair of running shoes, doing up a brasserie, going out for supper or crossing a street. Handling a fork, pushing the floor pedals of a car, reaching up into a cupboard to get a glass, or dialing a telephone number became, for some patients, impossible tasks to achieve. SCI patients experienced many disappointments, and they had to learn different means for managing their health needs and still remain civil to others when their attempts failed. Unfortunately, each disappointment confirmed their potential limitations. SCI patients reacted to their disappointing situations by swearing. Swearing was an adult coping mechanism they used to deal with their perceived personal failures.

The patients were angry that they had broken their backs. They felt that they had being "dealt a rotten deck of cards," or "got the short end of a stick," and would have done anything to undo the injury, no matter how long since the time of the accident. SCI patients protected themselves from the realities of their situations they found to be unbelievable by swearing. Swearing to one's self served to build a facade around the raw areas inside that were still bleeding, with such harmful realization that there would be people they would meet that would reject them because they were disabled and with the realization that they would never be able to walk as they once could. Swearing was an expression of this dispair, a release, a substitute for crying.

Good Days And Bad Days

All of the SCI patients said that they had "good" and "bad" days. Generally, good days occurred when something novel happened, when they found new activities to participate in and when the patients felt energized. Also, SCI patients said that a good

day occurred when they had a good night sleep, could sleep in on the weekends, completed a task in therapy classes they had never accomplished before, their bowel routine took a short period of time, had a bath day, received good news from others or went out on weekend passes. The patients said that on a good day they were more talkative because they were in "good spirits." When some of the patients discussed their experiences on good days they said,

> People can tell when I am having a good day. I talk more and I am around people. I don't spend as much time in my room.

> It's when I feel good about things in general. A good day feels good inside, and those days bring me more energy to carry on. I feel more optimistic about things then.

Most of the patients said that they experienced more bad days than good days because it was a constant struggle for them to perform tasks they once took for granted, such as, washing their hair, dressing themselves, or driving a vehicle. The SCI patients said that they had bad days during their rehabilitation program when they had a lot of spare time and were bored, had to return to the SCI unit from weekend passes because coming back to an institution depressed them, or when they felt ill or had setbacks, such as, a bladder or bowel infection. Also, sometimes a bad day for the patients occurred when their personal items were misplaced and they could not find these items, when nothing went smoothly with attempts to carry out their daily activities, they had slept poorly during the night, or they lacked motivation to keep on working towards improved functioning because they felt like giving up. All the SCI patients said that they felt frustrated on bad days. When some of the patients discussed their experiences on bad days they said,

> A bad day is when you have time to kill, you're bored with everything, you can't think of what to do, and you start getting lonely or thinking about something that's sad.

> Not feeling good. I'm not getting around very well. I don't like to be with people much. I don't talk as much and feel depressed. That's a bad day.
>
> A bad day is when you just have trouble doing everything you do. Sometimes it's really depressing because they can go on for quite sometime. A bad day is when nothing goes right, which is a lot around here.

The patients' circumstances determined whether they felt that they had good or bad day. Good days contributed to SCI patients' happiness and these days encouraged them to work harder at achieving their personal goals; whereas, bad days altered their willingness to continue with their rehabilitation program to the point of non-participation. When the patients had good days, they felt better about themselves, were less depressed about their predicament, and, inturn, experienced a sense of control to manage their limitations. Happy situations improved their self-worth, whereas, depressing circumstances hindered their progress in their rehabilitation program.

As the patients' functioning gradually improved, and they had the opportunity to exhibit drive, pride, and self-esteem, they developed a healthy defense for coping with their injury. They recognized the presence of their limitations; however, in order to go on, they were required to develop internal resources. Physical return, functional improvements, and increased levels of independence were placed in proper perspective when the patients had good days; on bad days, they attempted to conceal or negate the impact of the loss of certain abilities and refused to assign new meaning to their life. SCI patients were faced with rebuilding their self-image to feel proud and good about themselves which meant a shift from " what a person does" to "who a person is" on bad days.

The Modification Of Hope

Close acquaintance with the people on the unit revealed that hope was constantly being modified by the SCI patients, staff, and family members because of the day-to-

day reality of rehabilitation which consisted of post intensive care, comprehending the injury, on the SCI unit, and prior to discharge (see Table 4).

Post Intensive Care

When SCI patients talked about the time they were in acute care health institutions, specifically post intensive care, they spoke of their hope in terms of hoping to walk out and leave the hospital as soon as possible. They wondered, "When will I walk?" Hope arose at a time when the patients were being tested, a period of suffering and a state of being captive. Being reliant on others played a large part in determining aspects of their hope. Hope began to assert itself in the patients when they realized that they no longer had personal control over their life. For them, hope became a reaction to their abnormal situations. SCI patients believed no matter how dark things appeared there was an escape and that their present situations were not final.

Family members were curious about how long their relative would be hospitalized and hoped it would only be for a few days. They thought that within hours their child would be able to move his or her limbs once again. The emotional shock of facing the fact that the person they brought into this world and loved was now too incapacitated to even feed him or herself was too great to bear.

Staff members hoped that the injury was not permanent. They knew that if the patient had severed a spinal cord the damage to the spine would be permanent; consequently, they always hoped this was not the case. They were also aware of the lengthy hospitalization that would be required and the potential health risks SCI patients faced as a consequence of their accident. For the staff, hope was an expression of their desire not to see anyone's life limited.

Comprehending the Injury

Approximately four to six weeks post injury, when most of the necessary tests had been performed and the neurosurgeons had told the patients the extensiveness of

Table 4: *The Modification of Hope From Post Intensive Care To Discharge*

Person	Stage of Rehabilitation			
	Post Intensive Care	Comprehending the Injury	On the SCI Unit	Prior to Discharge
Patient				
Statement	I hope I can walk and get out of here soon.	I hope I die rather than be paralyzed for life.	I hope I can get back as much as possible.	I hope I can manage.
Question	When will I walk?	Is this really true?	How much will I get back?	Will I be able to make it?
Family Member				
Statement	I hope that he/she will be out of here soon.	I hope that he/she dies rather than be paralyzed for life.	I hope that he/she can do as much as possible.	I hope we make it as family/couple.
Question	When will he/she be out of here?	Is this really happening to us?	How much will I have to do?	What will become of us?
Staff Member				
Statement	I hope the injury is not permanent.	I hope that he/she is a para vs a quad.	I hope that he/she becomes as independent as possible.	I hope that he/she makes it.
Question	What is the extent of the injury?	I wonder just how permanent the injury is?	How far can I push him or her?	What will become of him or her?

their injuries, the pragmatic concerns on the part of the SCI persons were prefaced by the question "Is this really true?" Comprehension of their injuries had not been realized and patients spoke about their hope in terms of wanting to die rather than to be paralyzed for life. One patient said,

> When the doctor told me that my back was broken and I may never walk, I didn't want to believe it. Who would? The first thing I wanted to do was die right then and there. I couldn't even imagine a life without my legs.

When the unfavorable diagnosis was confirmed, the patients and their family members, particularly the mothers, began to fantasize about death, or else they denied the diagnosis was actually true. They were in a state of disbelief. For the patients, the question "Is this really true?" was raised, and for the parents "Is this really happening to us?" became an issue.

The staff, whether it was the doctors, psychologist, social worker, physiotherapists or occupational therapists, or staff nurses never knew exactly how much function a person with an incomplete back injury would eventually regain; even so, they hoped that every patient would regain maximum sensory and motor control. If patients had any damage to their spine, the staff all hoped that the extent of the injury would render the individuals a "para" versus a "quad." Paras were considered to have more functional ability than quads; however, staff on the unit mentioned that the recovery of a person depended upon their preaccident personality. How an individual had responded to previous situations and the coping mechanisms he or she used were considered the basis for responding to rehabilitation:

> Patient : I deal with each day the same way I did before my accident. I always had to work hard. My folks taught me to go after what I want. It's no different being in a chair now. It just means that I have to continue to go after what I want only in a different way.
>
> Father : My son was never a quitter. You know, when he comes home on weekend passes, I see how he

> problem-solves. He still has to deal with the same things every person does, like finding a job, owning a home, maybe raising kids. How he arrives at the solutions may be different than someone who can walk, but he approaches things now with the same determination and will as he did before he was hurt.

Staff : I don't see any difference between females and males reactions to rehab or their initiative. A lot depends on what their pre-accident personality was in relation to how well they do in the program.

> I think they all have difficulty accepting their injury, and it depends on the pre-morbid personality as to how well someone's going to accept the injury.

On the SCI Unit

During their rehabilitation on the SCI Unit, the patients hoped for the return of functional ability so that they could become as independent as possible. For example, they hated having to ask someone to clean them, to put their clothes on, to feed them, or to put them to bed. The patients wondered, "Just how much will I get back?"

Family members were concerned with "How much will I have to do?" For example, when their husbands were hospitalized, some wives were faced with added role responsibilities, such as, cutting the grass, paying the bills, raising the children, and getting the groceries. All the wives interviewed in this study found these obligations overwhelming. One wife said,

> I never knew just how much my husband really did in the marriage until I had to start taking over. It's a big responsibility to look after a home and raise the kids plus worry about your husband's condition. There were times, and still are, when I cry myself to sleep.

The hospital stay was lengthy for SCI patients. This placed health team members in a position to engage in the hoping process. Staff, not unlike the patients and family members, hoped that the patients would became as independent as possible. When the patients or family members experienced setbacks and were less motivated to participate in the rehabilitation program, staff wondered, "How far can I push them?"

The staff-patient and staff-family relationships formed the nucleus of hoping activity as the patient and his or her family had to expand the boundaries of the possible or face up to the realities of the impossible.

Prior to Discharge

Prior to discharge, the patients' hope was once again redefined to wondering if they would be able to cope in the mainstream of society. They hoped that they would manage and were concerned about "making it." All the SCI patients said that they felt optimistic about their predicament when leaving the unit by hoping for successful management of their limitations.

Family members' hope was redefined to wondering whether they would manage the predicament of a SCI when their relatives were preparing to live in their home. Family members hoped that they would be able to adjust to the changes and remain as a family or couple. They were unsure about "What will become of us?" in the future.

The staff hoped that every patient and their family would succeed in living a fulfilled life when these individuals were preparing to leave the unit. All the staff members said that they hoped the patients and their relatives "make it as a family or couple." Staff members never found out what became of them unless former patients or family members kept in touch.

No matter how long since the injury or the duration of their stay, not one patient, staff, or family member ever stopped hoping. Hope was an integral part of their existence. People had hope all the time, but they hoped for different things at different times. Everyone's hope was an on-going process, but the content of hope kept changing according to each person's circumstances. In situations where the reality of the situation was denied, true hope was replaced by false hope. For example, when patients were told the truth about not being able to walk, they persisted in false hopes that were based upon lies they had heard from others. One visitor said, "You bet you'll

walk again. I know a person who was in a car accident and had their back badly broken. The doctors told this person that they would be paralyzed for life. Kathy went for some type of treatment in the States and she walked." The recovery experienced by patients was individual and depended upon whether they sustained a complete or incomplete back injury, the area of the spinal column involved, and their use of previous or new effective coping strategies; so, although the visitor told the patient what they wanted to hear, the misconception of equating Kathy's situation to this patient's predicament was misleading and created false hope.

As reality encroached upon their situations, the patients began to define their expectations in terms of the remaining possibilities. For example, as patients strived towards reality-oriented goals, they appreciated more what was possible and excluded those things that were no longer in their grasp.

"Fear of the unknown" and "setbacks" were an integral part of having a SCI. Hoping did much to buffer the emotional shock and mitigate the physical suffering which impaired the health of SCI patients. Reality became a healing factor for those who were without hope at the time when the incident occurred. The expectation of change was called into play. A comparison in the way things used to be and their new reality brought about the hope for change.

With hope was attached a sense of mystery: the uncertainty of not knowing whether things would materialize or not. Hope involved actively waiting for something to happen. One person's opinion was another person's speculation; yet hope was a fundamental part of every person's being. Hope concerned a subject (the person who hopes) and an object (the particular thing the subject hoped for).

Having hope created a plan of action, which resulted in goal-oriented, integrating behavior and it was considered critical to everyone's health and well-being. On the part of the staff, the state of hospitalized captivity was a summons for action, for

professional interference. It was necessary for the patients and their family to recognize their captive state, but they also had to deal with it as an integral part of their lives. Then and only then did hope begin to exert a positive influence on their life. Interpersonal relationships with the staff contributed to the patients perceived notion of themselves as human beings and their contextual definition of hope.

The hope that SCI patients experienced was dynamic and directional and had a definite relationship to health. Their hope was equated with positive expectations of future events. Its content was continually being modified. Everyday they had new expectations, and everyday they revised their hopes. Hope had momentum which implied such expressions as "Everything will get better," and "If you hope for more, anything that comes back will be a bonus." For some, hope encompassed a religious orientation. Sometimes patients felt that the only hope they had left was "God still cares and if he has the power to help me walk again he will."

All patients wanted to measure improvements in their lives, such as, being able to transfer from their bed to their chair with ease, having a bowel movement that only took ten minutes, or being able to dress themselves. These accomplishments may be insignificant to an outsider, and even overlooked, but the small things in a SCI person's life became extremely important to them in making decisions about what they could and could not do, where they could and could not go, and when they could or could not do something. As one patient said, "It is impossible for anyone in life to go on without hope. Once you stop hoping you stop living." SCI patients hoped for better health so that they could begin or continue an intimate relationship, be employed, or manage some of their household responsibilities.

One of the parents interviewed suggested that hope could be summed up as "There is much more than meets the eye of a person's capabilities. You really never know just how much a person can do until they are faced with having to attempt it."

What this parent was referring to was the expansion of the boundaries of SCI people and their potential for further accomplishments. Hope involved a push beyond what appeared to be obvious limitations. Hope created the courage to proceed into the unknown; a reorientation of possibilities.

Hope was shared among all the people on the unit. For example, two patients who had been on the unit for four months, were positioned in the smokeroom. These patients discussed the importance of hope:

> B: It just sucks being in the chair. Why is it some people are given a second chance to walk again? Take the paras, they may not walk like they used to. Some of them have to use canes or crutches to walk again, but they still have the feeling of walking. It just seems so unfair.
>
> L: Who knows. You have to have the will to fight and hope for more or else our lives will be meaningless to us. Don't ever give up. It's too important.

Hoping was reciprocal, and the struggle to overcome the seemingly impossible was maintained only as long as each person had empathy for the other, and vice versa. The presence of hope in the staff, SCI patients and their relatives promoted the development of interpersonal relationships on the unit. A bond formed between people who hoped and the maintenance of this bond was based on individuals' strengths and weaknesses

The prolonged contact that nurses had with SCI patients placed them in a favorable position to participate in the process of hope. However, to become more effective participants, it was important for nurses to be aware of themselves as human beings with feelings. Following this, an interpersonal relationship was established between the nurses and SCI patients based upon genuine care and concern of one human being towards another. The nurse's awareness of self as a person and as a professional influenced SCI persons' understanding of themselves.

The nurses came to the patient with hopes and the patients responded to the nurses' attitudes of encouragement by, in turn, building their own hopes. The better nurses understood the dynamics of the hoping process, the more effectively they were able to assist patients in working through a time of crisis. The presence of hope was a powerful force on the unit in terms of interpersonal relationships, rehabilitation and recovery. It is from such a foundation that hope was experienced in this study.

Leaving The SCI Unit

Prior to discharge, SCI patients said that they had ambivalent feelings about leaving the unit. They were glad to be relocating themselves with their family and friends; however, they were also afraid about not "being able to manage." They recognized that staff members had provided them with some of the knowledge for dealing with their future situations, but they were unsure about how they would cope with unknown circumstances. Above all, SCI patients feared not making it in the outside world. The patients felt that they were different from people who were not injured, and they believed their chances of leading a normal, productive life was slim.

Sustaining a spine injury was a devastating experience for the SCI patients. The injury produced immediate consequences of immobility for them that were often irreversible and affected all aspects of their lives. Alterations in the ability to move about or to function within their family unit had a direct effect on the patients' emotional well-being. The need to depend on others to perform certain day-to-day activities was difficult for SCI patients and they felt helpless having to rely on others to complete certain tasks. As they learnt to manage their limitations during rehabilitation they, in turn, gained more control over their predicament and achieved an increased level of independent functioning.

The social meaning of having a SCI injury took form through interaction with other people in public places and resulted in a new social identity. The SCI patients'

presentation of limitations and the reactions of others to them influenced the development of the patients' self-image. The patients acknowledged that altered behavioral expectations meant redefining their social role. Consequently, their perceptions changed, as did their behavior, and their performance was affected by the development of a new self-identity, with expectations of being integrated back into the mainstream of society. The reactions of persons outside the SCI unit meant everything to the patients as they considered these reactions to be reality-based compared to the relationships that they developed in the confines of health institutions. The patients desired to be part of society, yet they feared rejection. Social acceptance was the key for the patients to adapt to their predicament prior to and when they left the unit, and this acceptance required continued learning about and adaptation to their limitations.

Summary

The experience of the SCI patients from the time of their accident to the time they left the unit has been presented in this chapter. During rehabilitation, SCI patients experienced many changes with respect to their social, physical, and emotional well-being. SCI patients, their friends, staff, and family members held significant beliefs about the experience of sustaining a spine injury and the process of rehabilitation. A variety of prescriptions and restrictions believed to be important have been identified by each of these individuals. In addition, the patients' experiences related to managing their injury have been described. SCI patients made their own discoveries about conducting their day-to-day activities and relied on these experiences during their rehabilitation program to validate the existence of their limitations. The significance of these findings are discussed in Chapter VI.

VI. DISCUSSION

The purpose of this study was to examine the experience of sustaining damage to the spine from the perspective of SCI patients. An inductive approach was used because an analysis of existing research on SCI patients revealed that studies investigating the predicament of being a SCI patient in a rehabilitation institution were virtually non-existent. The findings of this study indicate that SCI patients have a complex belief system related to their injury and involvement in the process of rehabilitation. Developing an understanding of what it is like to experience a spine injury has important implications for rehabilitation nursing services and is clearly an integral part of understanding the phenomena of SCI patients.

The purpose of this chapter is to discuss the findings of this study from the time of the patients' accident to the time they leave the SCI unit. This discussion is organized as follows: discussion of the research methods, discussion of the findings, implications for nursing education, implications for nursing practice, suggestions for future research, and a summary.

Discussion Of The Research Methods

Method

The ethnographic method was used in this study because it allowed the researcher to explore SCI patients', their friends', staffs' and family members' concepts about damage to the spine by eliciting and analyzing their own words and frames of reference. This method is based on an ideological approach to culture which assumes that culture is composed of psychological structures by which individuals or groups of individuals guide their behavior and share a specific social, psychological, and cultural problem that is not necessarily articulated. Hence, it was necessary to understand the thoughts and

feelings associated with a spine injury from the perpective of the individuals who had experienced it. Using the enthnography approach, the researcher strives to reveal the most salient issues and concepts that are significant from the subject's cognitive perspective; consequently, this approach was useful and consistent with the purpose of this research. The findings in this study do not represent the beliefs of any one individual, but they describe the common beliefs derived from all the subjects who participated in the investigation. Although this approach has the potential of obscuring contradictions that existed between individuals, attempts have been made to elicit and explain variations between the informants' belief systems (Aamodt, 1982; Davis, 1986). The degree to which behavioral events can be predicted from knowledge of cultural rules remains a topic of debate (Aamodt, 1982; Davis, 1986; Field, 1983).

Data Collection Techniques

In this study, data were collected using unstructured interviews, participant observation, and field notes. The use of unstructured interviews made it possible to fully explore the implications of a spine injury using the language of the informants. As more data were collected, patterns of the SCI patients' experiences in a rehabilitation institution emerged. The flexibility of unstructured interviews and participant observation allowed the verification of these patterns by the use of probing questions. Additional interviews with the SCI patients' friends, staff, and family members elucidated these patterns with respect to their views of this predicament. A further technique of using secondary informants provided corroborative evidence of the SCI patients' day-to-day practices and beliefs.

All interviews were conducted on the SCI unit. Although this environment provided a relaxed, convenient, and comfortable environment in which to conduct these interviews, there were times when the setting hindered privacy. Occasionally, informants were distracted by telephones, visitors, and time constraints. To overcome such

obstacles, more interviews were held with these particular informants. Participating in this study provided the SCI patients, their friends, staff, and family members the opportunity to reflect on their own beliefs and experiences. This was something they did not often discuss with others, and all participants requested the opportunity to share their ideas with someone whom they perceived to be less involved (i.e., the researcher). As a result, the informants said that they felt at liberty to disclose information they would normally be uncomfortable sharing with others. Informants were comfortable within this setting and were relaxed during interviews. Given that they had at their disposal the necessary equipment and facilities, the SCI unit enabled participants to illustrate certain practices by demonstrating them (i.e., physiotherapy and occupational therapy classes or meal times). Furthermore, the researcher was able to observe informants' behavior in the naturalistic setting.

Generalizability of the findings was not the goal of this study. As the sample size was limited to a volunteer sample from one institution, no attempt was made to quantify any of the characteristics that were described. Informants were selected by the researcher for their potential knowledge and for their interest in sharing it. Accordingly, the specific characteristics of the informants may limit the generalizability of this investigation. For example, individuals who were in the acute phase of a rehabilitation program were not included in this study. Therefore, the findings of this research may not apply to individuals who were in other phases of rehabilitation programs specific to SCI patients.

This investigation does, however, permit theoretical generalizability. A study can demonstrate theoretical generalizability when aspects of the emergent concepts can be applied to the experiences of other individuals. The utilization of secondary informants was a means by which the findings of this study were checked to ensure that they "made sense." Applicability of the findings may be relevant to other individuals in crisis

situations, such as, persons who experience the sudden loss of a limb because of amputation, a burn, or a physiological disorder.

A potential limitation of unstructured interviews and participant observation was the reactive effect which the researcher can impose (Denzin, 1970; McCall & Simons, 1969; Wax, 1971). As both of the research methods used in this study were interactive by nature, researcher biases could potentially have been imposed on the responses elicited. However, the use of theoretical sampling and rechecking observations and responses, which is an integral part of the ethnographic approach, ensured that the potential effects of the researcher were limited. On-going discussions with the thesis committee members, professional colleagues, and secondary informants further contributed to the potential of accurately reporting the characteristics of the participants in this study. Having shared the findings of this study with a number of individuals, this researcher has been impressed by the fact that the findings were considered to be extremely relevant. Comments from these individuals like "that's exactly how it is," "it makes perfect sense to me," and "that's the way it is" were indications that the findings of this study reflect the reality of the informants' experiences.

Although some informants were initially reluctant to participate, the week spent on the SCI unit prior to the commencement of data collection and multiple interviews enabled a trusting relationship to be established with the researcher. As the informants became more relaxed with having a researcher around, they were able to express their own views. This was confirmed by the fact that the participants said that they felt free to point out gaps in the data until no new information was obtained.

Finally, it must be recognized that this study is a beginning step to understanding the experience of SCI patients in a rehabilitation institution. To develop a broader scope of the implications of a spine injury, further research is needed to explore the phenomena of this predicament in the acute stage of recovery, as well as, the experience of the

patients after they leave a SCI rehabilitation unit. Despite the limitations, this study was significant. This study has documented the features of a SCI unit, the characteristics of the individuals who used these facilities, a normal day on the SCI unit, and the beliefs and practices of a group of SCI patients. This is information that has not been previously documented from the perspectives of the informants themselves.

Discussion Of Findings

Features of the SCI Unit

This study was unique because, to the knowledge of this investigator, there was no previous ethnographic investigation of a SCI rehabilitation unit. A detailed description of the facilities on the SCI rehabilitation unit, their use, and the activities of individuals that normally take place on the unit have never been studied in this context. The SCI patients considered some of the features of the unit a hinderence, such as, the limited space for the washrooms, limited areas for socializing, and lack of storage space. These restrictions had implications for their adaptation to their surroundings and affected their emotional and social well-being.

More importantly, the findings in this study revealed that this particular group of SCI patients experienced changes in their lives during the rehabilitation process in the postacute phase of recovery. The SCI patients said that the major changes they exerienced was assuming the patient role and a new lifestyle. Research on patient role (Brink & Saunders, 1976; Brown, 1964; English & Morris, 1988; Mauksh, 1962; Nagler, 1950) and the informants in this study revealed that many changes have taken place in health care practices for SCI patients. Some of these changes included an emphasis on self-care and a new public awareness of the disabled person. SCI patients said that changes in health care practices influenced their progress during rehabilitation. Some of the changes in health care practices for SCI patients have coincided with the modernization of the SCI community, advances in technology, advances in the delivery

of patient care, such as, stabalizing the spinal cord, and the introduction of government policies with respect to the disabled person. The effect of the changing health, educational, and social systems on group solidarity, health, and family relations for SCI individuals was beyond the scope of this research and warrants further investigation.

Cultural practices and beliefs guided the development of important issues for SCI patients, such as, the use of equipment, social integration, and the transition from the institution to the community. These issues were not without consequences for the SCI patients during the rehabilitation program, such as, the patients feeling self-disgust when they experienced accidents with their equipment and having to build facades to hide their inner most feelings from others. Germain (1979) stated that present day health practices follow a technological approach to rehabilitation, that is, an approach that focuses more on machines and equipment for long-term patients than the individuals themselves. For this group of SCI patients, the technological aspect of rehabilitation was overwhelming. Informants' descriptions of feeling humiliated and depressed due to line-ups for food in the cafeteria or washrooms provided evidence that present institutional facilities were not meeting the SCI patients' emotional needs. Having to line-up for food and bathroom facilities contributed to the SCI patients feeling like second class citizens. Research has indicated that patients' experiences in health care facilities can influence the development of their self-worth, confidence, their ability to recover, and may color future rehabilitation experiences (Brink & Saunders, 1976; Brown, 1964; Ciancutti, 1984; Germain, 1979; Kelly & May, 1982; Mauksh, 1962; Mead, 1976; Tagiliacozzo & Mauksh, 1972; Spector, 1985). Thus, rehabilitation care which addresses the psychological and emotional needs of individuals with spine injuries is crucial for SCI patients, staff, and family members. Further, it is important that expanded investigations be conducted to disclose the physical, psychological, and social ramifications of rehabilitation for SCI patients and their relatives from the time of the accident to community placement.

A Normal Day

SCI patients organized their day around their bowel and bladder routines in order to avoid urine and stool accidents. They wore special equipment, such as leg bags, when they socialized with others outside the confines of the unit, wore slacks to conceal this equipment, delayed drinking after midnight, and used the washrooms before leaving the unit in order to avoid embarrassing intestinal leakage in public. The SCI patients described the management of their bowel and bladder as a routine personal care issue that affected their daily activities. As the patients' regulation of their bowel and bladder were brought under control by physical, nutritional, and educational means, the patients became more comfortable with these particular health care practices. When the SCI patients were ill and experienced consecutive days of body fluid loss, it became a serious management problem, and for some, it limited them to bed rest. The findings of this study not only allude to the disruption, health risks, and fear of loosing control over circumstances that were considered to be of a private nature, but they also reveal how the behavior of SCI patients was interpreted by others inside and outside an institutional setting. Bowel and bladder routines referred to behaviors SCI patients used to control for potentially unexpected embarrassing moments because of the demeaning effect these situations had on them, whereby, they felt reduced to infants. The findings of this study indicate that "getting regulated" was a strategy SCI patients used to maintain the facade of being in control while hiding one of their greatest fears of experiencing a bowel or bladder accident.

Bedbrook (1985) found that SCI patients with bowel and bladder inconsistencies reported lower levels of social activity and were potential risks for other health complications. These findings suggest that the impact of bowel and bladder regulation was an important issue for individuals with a spine injury. The findings in this investigation also indicate that SCI patients experienced bowel and bladder

inconsistencies and warrants further investigation for appropriate and beneficial health care interventions not only instituted within the confines of health care institutions. In order to eliminate the potential risks of accidents occurring in public, further investigation is necessary into the possibility of improving the portability and appearance of equipment, such as, catheters, leg bags, and incontinent pads.

In the literature, social isolation was frequently attributed to bowel and bladder incontinence because researchers have failed to clarify the reason why SCI patients spent a lot of time at home. The findings in this study indicate that SCI patients were required to make special arrangements when socializing outside the boundaries of the SCI unit or if they planned a holiday. Further research is needed to explore the consequences of social isolation due to bowel and bladder incontinence for individuals who have sustained permanent damage to the spine.

Bowel and bladder management was a very private problem, a subject that was usually not openly discussed by the SCI patients. Waters (1987) described the concealment of information by SCI patients as a psychological approach they used to deal with sensitive issues. The humiliation and embarrassment associated with unexpected urine and stool accidents were identified by most patients in this study, and they stated that they seldom discussed these problems with anyone. They would tell the orderly attendants what they found to be helpful with the management of their bowels and bladder and no more. Most of the patients said that it was beneficial to have someone else to talk to, such as, the other patients, with whom to share their experiences and compare notes. In addition, some of the informants commented that it was easy to talk to the researcher about these issues because they felt the researcher was in a neutral position and would portray their concerns objectively. SCI patients feared discussing such topics with others because they believed people would perceive them as emotionally weak. These comments point to the need for nursing services that provide opportunities for SCI

patients, individually or in groups, to discuss their concerns and obtain accurate information from health professionals.

Most of the patients described their bowel and urine management as stressful activities and were discouraged when they experienced set backs, such as, urinary infections or malfunctions in their equipment. Holt , Matthews, and Carlson (1987) reported similar findings, but they believed these feelings represented a healthy response for protecting the patients' self-worth. Although it was evident that SCI patients developed coping strategies to deal with their predicament, it is beyond the scope of this study to draw conclusions about the feelings described by the SCI patients. The challenge for health professionals is to be able to provide care that promotes rather than threatens the SCI patient's independence.

There was reference in the literature to the variety of equipment available to SCI patients, such as, eating utensils, wheelchairs, canes, braces, cuffs for the hands, and external urinary devices (Boyink & Strawn, 1981; Capildeo & Maxwell, 1984; Cook, 1976; Stryker, 1977). For many patients, incontinent pads were readily available in the knapsacks of their wheelchairs. Male and female patients used leg bags, but they were considered to be clumsy, awkward, and embarrassing to wear. The fact that SCI patients used a variety of equipment in different situations warrants further investigations as to their applicability and practicality of use. This is clearly an area that deserves attention because of its implications for the SCI patient's self-worth and body image. The informants in this study provided new information about the product needs of SCI persons and there is a need for further investigation in this area.

Recollections

The Incident

The sudden nature of a spinal cord injury constituted a crisis which disrupted and changed an individual's life; consequently, the future was perceived to be uncertain by

the SCI patients in this study. Immediately after the accident, all the patients fought for survival until they were stabilized in the emergency department. It was interesting to note that ambulance drivers helped the patients to recall their accident once they were in the intensive care or when they were in the step-down neurosurgical wards. The implication for integration of ambulance drivers into rehabilitation programs needs to be further explored with regards to their impact on the rehabilitation experience for SCI patients. Research has acknowledged the important role that emergency attendants have in a crisis situation, especially with respect to the medical interventions and the survival techniques they employ (Bartol, 1978; Boyink & Strawn, 1981; Cartwright, 1964; Ciancutti, 1984; Guttman, 1976); however, no studies have investigated the psychological, social, and educational contributions of these attendants during the rehabilitation process.

The Acute Phase of Recovery

During the patient's stay in the intensive care unit, staff efforts were dedicated to resuscitating and stabilizing the spine injury. The staff's preoccupation with the technical aspect of caring for SCI patients during this time has been suggested as a defense mechanism to assist them to cope with the nature of their work (Weller & Miller, 1977). Although this "busyness" reasurred patients, if carried to the extreme, the patients reported that it made them feel isolated and increased their anxiety. Health team members were part of the patient's environment; accordingly, the findings in this study revealed professional behavior influenced the patients' adaptation to their injury.

The informants described their reactions to care during the acute and postacute phase of recovery in terms, such as, shock, disbelief, anger, depression, and acceptance. These terms corresponded to the stages of grief responses addressed in the literature on long-term illness and disability (Bowlby, 1973; Carlson, 1978; Kubler-Ross, 1975; Worden, 1982). Although this framework was useful for identifying and understanding behavior and in planning intervention, further research is needed to explore the SCI

patients' grieving responses during the process of rehabilitation. The research literature that addressed the issue of SCI patients' adaptation to their injury presented a confusing picture as the conceptual definitions of grief, and the identified stages of grief responses used vary widely. Further research is warranted to investigate the implications of patients' responses to their injury and health care during all phases of rehabilitation, including their experiences in the community.

The devastation that a SCI imposes on the affected individual and the people who they care about is impossible to ignore. The majority of the patients in this study were in the active, productive period of life when this major trauma occured. Failure to provide appropriate care at any stage of rehabilitation could inhibit the patients' ability to lead healthy, fulfilling and productive lives. To achieve this goal, further research is needed to address the acute stage of recovery for SCI patients. This study focused on the postacute stage of rehabilitation and is a beginning step towards understanding the particular health problem of a spine injury.

Arrival to the SCI Unit

The Postacute Phase of Recovery

The findings in this study indicate that SCI patients experienced changes in their roles as a result of a spine injury. The patients were immediately stripped of their former roles the moment they were admitted to health care facilities. They were stripped of the power to make decisions and were instructed on what to do and how to do it. Responsibility for the patients' health was taken over by members of the health care team. The SCI patients could not regain personal control of their predicament until they began to take charge of their own circumstances. As it was conceptualized in this study, "taking charge" involved the patient making decisions about the management of their injury.

Several investigators' work pertained to the concept of personal control (Brown, 1964; Cartwright, 1964; Ciancutti, 1984; Dorroh, 1974; Parsons, 1951). Carwright (1964) suggested that personal control affected the coping behaviors that an individual used when he or she was under stress. In a similar manner, Dorroh (1974) described taking charge of one's life in terms of independent function. This author stated that people in control of their situations, because of independent actions, experienced a strong sense of determination and will to succeed in their personal goals. The findings of this study suggest that taking charge of one's predicament was a necessary dimension of gaining personal control. Equally important to the informant's sense of taking charge were the dimensions of independent function. Control over the nature of the injury was not viewed by the SCI patients as an achievable goal; however, the ability to plan strategies to manage the injury was seen as a means by which control could be regained.

In order to re-establish control of their predicament, SCI patients required an adequate knowledge base. The patients in this investigation believed that they knew very little about the consequences of their injury. A growing body of literature recognized the fact that SCI patients need extensive education (Bartol, 1978; Bedbrook, 1985; Boyink & Strawn, 1981; Capildeo & Maxwell, 1984; Comarr & Vigue, 1978; Holt, Matthews, & Carlson, 1987; Seidel, 1982; Trieschmann, 1980). However, four questions continue to be raised in the literature: In rehabilitation programs, what information benefits patients? At what stage of rehabilitation does this information benefit patients? What mode of instruction do SCI patients benefit from the most? How much information should be shared at one time? The findings of this study suggest that the importance of education for the informants is related to the extent to which they believed the information was meaningful to them and contributed to their independent function. Information that did not fulfill these needs was forgotten or served to increase the informants' anxiety and, in turn, their loss of personal control.

A recent investigation (Waters, 1987), which focused on the experience of individuals involvement in rehabilitation programs, found that the greater an individual's control of their circumstances, the better were his or her chances of coping. Furthermore, this researcher found that dependency on rehabilitation institutions was detrimental to successful readjustment. There was apparent conflict between the role of professionals imparting knowledge and the patient's need to take charge of their learning requirements. This was further substantiated by the research of Trieschmann (1980) who described situations in which health team members held strong beliefs about what constituted effective treatment regimens, with an overemphasis on what the SCI patients should do to manage their day-to-day activities without regard to initially assessing their learning needs. These circumstances can lead to what Comarr and Vigue (1978) alluded to as compliance of routines without full understanding of their merit. It was primarily through trial and error that the informants in this investigation developed meaning about their injury and strategies to cope with their situation. Adjustment to a SCI cannot be based solely on the information from health care professionals, but such information did provide opportunities for the patients to test their limitations and learn about their predicament.

The Loss

As many changes were imposed because of the losses endured as a result of damage to the spine, living with a SCI injury was a challenge to the patients and their families. The results of this study revealed that the SCI patient and their family members were affected by and responded to this challenge in several different ways. SCI patients had to learn to incorporate the rehabilitation regimen, schedules, classes, roles, and responsibilities into their existing relationships and lifestyles.

Although some of the family members had been taught certain treatments to follow when their relative came home on weekends passes or in preparation for

discharge, in this investigation these individuals took on caregiver responsibilities. These responsibilities included preparing meals, assisting in morning and evening care, transfers, and bathing and required that the family members did many extra tasks that consumed time and energy. The findings in this study revealed that the feelings of "overwhelming" responsibility for the life of their relative during the postacute phase of rehabilitation resulted in feelings of anxiety, resentment, and guilt. These results were similar to a study conducted by Weller and Miller (1977), who found that family members did not consciously decide to assume added responsibilities for their relative, but even though they expressed fears about "doing" or "saying" the wrong thing, they naturally assumed it was their duty as parents to help their child with whatever was necessary. Wing (1977) suggested that not being able to conduct previous day-to-day activities, as in the case of SCI patients, resulted in loss of former abilities and said that the added stress experienced by family members could be a result of them assuming more responsibility for the care of their relative.

The family members in this study expressed a sense of loss not only for their child or spouse but for themselves as well. Changes in their home were reported. Research literature on coping strategies for families of SCI patients was virtually non-existent. The identification of adaptating strategies required by family members was addressed; however, further research is needed in order to understand the various strategies family members use to cope with the sudden and unexpected event of their relative's accident. Further it is important that expanded investigations be conducted to disclose the adjustment process for individuals, such as, girlfriends or boyfriends considering that in this study the majority of these individuals drifted away from their relationships with the SCI patients.

Sources of support were related to SCI patients' obvious need for support. In this study, the adolescent SCI patients felt most supported by their mothers. Their

fathers involvement meant a lot to them; however, when they became ill or a crisis took place, they generally turned to their mother for support. To the knowledge of this investigator, this finding has not been reported in any other research on SCI patients. Much of this could be attributed to the fact that limited investigation into family members' response to a SCI exists. Answers to questions about family members' experiences with a SCI, such as, Who do these family members receive support from?, Is there a difference for mothers and fathers?, and How do they come to terms with permanent disability? are areas for future nursing research. Results from this study which included changes in caregiving responsibilities, role transitions, and orientation to rehabilitation institutionalization were concerns for family members.

The Use of Language

When change, such as, a SCI injury occured, patients had to make a compensatory response in order to adapt (Fordyce, 1964). The adaptation to changes required that individuals develop strategies to deal with these differences in their lives (Cook, 1976). For example, SCI patients' day-to-day activities were redefined to include tasks, such as, transfers, the wearing of equipment, and attending classes.

Swearing was representative of a compensatory response to a crisis situation (Montagu, 1967). When an accident disrupted their function, normalcy was altered, and it was not until the temporary alteration of their system had passed that normalcy was restored. In the case of a SCI, the disruption was prolonged and sustained, causing the person to shift to new and different levels of normalcy, which involved new responses (Stryker, 1977). The individual had to find new strategies in order to create meaning in his or her life and to manage the uncertainty associated with change. The group of SCI patients in this study were in a state of constant change, with very little assurance that they could manage. Developing and evaluating effective strategies to recreate normalcy was a constant struggle. From the perspective of the SCI patients in this study, an aspect

of achieving normalcy was achieved by swearing, which served to build facades that made them appear normal. The findings indicate that swearing by SCI patients was a coping mechanism used to maintain the facade of normalcy while hiding their fears. This is a new finding in the field, never reported in previous investigations of spine injury.

The conceptualization of swearing may provide a useful means for examining and assessing the progress SCI patients make in the adjustment process following a SCI. Indices of improvement in the adaptation of a spine injury have been lacking in the field of spine injury rehabilitation. As health care professionals are continually challenged to demonstrate the value of their interventions, the implication of coping strategies, such as, swearing needs further investigation. Further research in this area could provide a more solid understanding of the role that swearing plays in the rehabilitation of SCI patients and may give nurses a better understanding of this strategy and the ways in which it could be enhanced.

The findings in this study indicate that the maintenance of personal space was an intrinsic dimension of the swearing process. Informants were acutely aware of personal space, which they referred to as "breathing room." Personal space has been defined by Douglas (1976) as "the area individuals protect to which others cannot intrude without their permission" (p. 176). He described the frequent use of the term "breathing room," but the researcher suggested that the analogy may not reflect the boundaries attributed to an individual's personal space. This researcher documented the major theoretical positions, salient variables to this concept, and the methodological and measurement problems of current research on personal space; however, no findings suggested the use of coping strategies when the boundaries of an individual's personal space was jeopardized. For SCI patients in this study, swearing served as an adult coping mechanism to maintain their personal space, maintain the comradery of the group, release emotions, and build facades. Unfortunately, it is beyond the scope of this study to

understand the full ramifications of this strategy with regards to its social, psychological, and physical implications. Further research in this area is warranted to explore the use of swearing by SCI patients, not only as it relates to the protection of their personal space but also how it relates to other circumstances where it may be found, such as, men's locker rooms, gambling casinos and pubs.

For nursing, one goal is to enhance the coping strategies that individuals utilize. The more understanding health care professionals have about the functions of the language of SCI patients, the more effective they could be in assisting the patients to manage the predicament of a spine injury. The findings in this study indicate that swearing by the SCI patients helped them to cope with their limitations during their rehabilitation program.

Hope

Not one patient, staff, or family member in this study ever stopped hoping any person with a back injury would walk again. Hope was an integral part of their existence. People had hope all the time, but they hoped for different things at different times. Everyone's hope was a continuous process, but the content of hope kept changing with each person's circumstances. An understanding of the role that hope plays in the coping strategies of individuals has not, to date, been explored among victims of a SCI.

The research literature on hope presented a confusing picture because the definitions of hope varied considerably. According to Miller (1985), hope was an intrinsic component of life and a powerful resource for decreasing powerlessness. Similarly, Hickey (1986) and Hinds (1984) suggested hope was anticipating the future and having something to look forward to. Conversely, hopelessness was considered a barrier to optimal quality of life and growth (Brandt, 1987). McGee (1984) described hope as the ingredient that enabled an individual to move from a state of weakness and vulnerability to a state of growth, with the ability to live as fully as possible. The

dimension of hope has been described as a highly subjective and multidimensional process (Breznitz, 1986; Miller, 1985). Hope is metaphorical, and this concept has been described as a protection, a bridge leading one from darkness to light, and an intention without fear (Breznitz, 1986). In light of these findings, hope became a means to cope with ongoing stress, as was the case with the informants in this investigation.

Investigators have used a variety of conceptual perpectives as frameworks to understand SCI patients' attempts to maintain self-preservation. Concepts such as, locus of control (Rotter, 1966), competence (Moos & Tsu, 1976), powerlessness (Seeman, 1959), hopelessness (Beck, Weissman, Lester, & Trexler, 1974), and learned helplessness (Seligman, 1975) have emerged as possible explanations for the role that hope plays in crisis situations. Holt, Matthews, & Carlson (1987) found that SCI patients exhibited low levels of hopelessness. Similar to these researchers, the finding of this research indicate that hope was constantly being modified and was always present to some degree. The findings by Breznitz (1986) supported the findings of this study by suggesting that hope can thrive concurrently with total helplessness in stressful situations. The informants in this study who were more doubtful and less hopeful were those who were often unable to establish personal goals; however, these individuals never "gave up" throughout the rehabilitation program. The findings of this study indicate that uncertainty, doubt, and anticipatory grief experienced by the SCI patients and their relatives were all effective behaviors indicative of adapting to the changes in their lives, and they reflected the feelings expressed in the dimension of the conceptualization of hope.

All the SCI patients in this study believed that hope was necessary for regaining control of their lives, and they believed that if they "gave up" it would be admitting defeat. The findings by Breznitz (1986) supported this notion by suggesting that hopelessness can be more detrimental to the patient than the crisis situation itself. SCI

patients fought to overcome their limitations and constantly projected hope to others. It is this investigator's contention that informants constantly fought their SCI by being hopeful. Further investigation of what hope means to SCI patients may provide nurses with the knowledge to assist SCI patients in adapting to the changes associated with a spine injury.

Discharge Planning

The major finding of this study relevant to the SCI patients discharge from the unit was that they had ambivalent feelings about leaving. Their expressed desire to leave may not represent the patients' readiness to return to the community. In order to assist patients in their transition to the "outside" world, assessment of their readiness to leave was a necessary activity by health professionals. Although SCI patients desired discharge, they feared not "making it" once they left. This study suggests that assessment of patients' strategies for attaining their personal goals once they were in the community may be the most comprehensive method for assessing their readiness to leave a rehabilitation unit.

The planning of realistic goals required that patients understood their ability to function in the community, and referrals to community agencies were based upon patient needs (Guttman, 1976). Research is beginning to demonstrate the shortcomings of discharge planning (Boyink & Strawn, 1981; Brink & Saunders, 1976; Capildeo & Maxwell, 1984; Orlando, 1961). Considering rehabilitation is geared to the integration of patients back into the community, investigations that address this issue are needed to fully assess how effective rehabilitation programs meet patients needs once they leave health care facilities. This study is limited to SCI patients in a rehabilitation unit prior to integration into the community. Thus, research that addresses the psychological, social, and educational needs of individuals with a spine injury prior to discharge and when they are back in the community could provide useful information for SCI patients, their family

members, and health professionals. Further, it is important that expanded investigations be conducted to disclose the implications of the rehabilitation process for these individuals from the time of the accident to community placement. The battle of overcoming limitations is difficult, and research activities that address the issues of change caused by a spine injury could only help those that work with SCI patients.

Implications For Nursing Education

The major implication arising from this study for nursing education was the need for content on effective communication styles to be formally incorporated into curricula. It was apparent from the findings of this study that communication with SCI patients and their relatives could be learned and that much of the learning is done informally. This latter point has implication for the manner in which communication is taught. If role modelling is one of the primary mechanisms of learning, then the role of nurse-educators is clearly an important one. Equally important is an understanding of the many variables that determine a nurse's communication style. The inference that can be drawn from this is that the exploration of how nurses interact and manage their work with SCI patients and their family members has implications for their involvement in rehabilitation programs.

One of the criticisms made by staff members in this study was in relation to their socialization into the role of a caregiver with patients who had a spine injury. If nurses are being educated with unrealistic expectations about SCI patients' abilities, and are not receiving assistance with the development of effective resources and strategies with which to manage difficult situations they encounter in their work place, then educators need to reexamine the content of nursing programs. The findings dealing with effective communication techniques, responses to crisis events, and grief are a rich source of material for nurse-educators concerned with communication. This investigator suggests that these dimensions may be neglected because they stir uncomfortable emotions in

nurses who are trying to come to terms with caring for SCI patients. The findings are also of particular relevance in terms of developing an understanding of SCI patients during the postacute phase of recovery and the subsequent ability to be aware of disruptions and progressions during rehabilitation. The multidisciplinary team approach to SCI patients' rehabilitation places staff members in a complex communication system; therefore, effective communication among all staff members could enhance their efforts to produce an integrative and beneficial rehabilitation program.

Implications For Nursing Practice

There were many implications for nursing practice arising from the findings of this study. The most important implication was understanding a SCI within the context of its culture. The development of nursing care, instructional practices, and enforcement of rules and regulations within the confines of health care institutions is important to be initiated in such a way that SCI patients are treated as human beings rather that innate objects without input about their predicament. The findings in this investigation indicate that unless patients participate in decisions about their care, they could be less committed to actively participate in their rehabilitation program.

Research has identified suggested improvements to hospital policies, community legislation, and protocols for SCI patients, which, if implemented, are intended to promote successful management of their injury (National Spinal Cord Model System Conference Proceedings, 1978). For example, one recommendation calls for the initiation of classes as soon as the SCI patient arrives at a rehabilitation institution. This particular recommendation was feasible for this group of SCI patients; however, the effectiveness of instruction at this time needs to be re-evaluated for three reasons. First, there is a belief among SCI patients that detailed information, such as, the anatomy and physiology of the spine, and the expectation that it is important for patients to attend such classes at this time is inappropriate. Most SCI patients said that this information was

important; however, they felt their comprehension of the information would be beneficial if it was spread out during their rehabilition program, particulary after they became comfortable with the unit. All the patients in this study were overwhelmed by their injury and their arrival at the unit. Second, SCI patients who reported their orientation to the unit and involvement with these classes said that the bombardment of information within the first two to four weeks of their stay and their low energy prevented full comprehension of the content. These patients said that they were too fatigued from their daily routines to successfully implement suggested protocols related to self-practices during their immediate postacute injury phase of recovery. Third, it is important to note that the patients reported they felt reluctant to ask questions because they were unfamiliar with the staff. Perhaps these patients would have been more comfortable if former SCI patients were involved in the planning and teaching of these classes.

Similarly, nurses and other health professionals could benefit by including SCI patients in all aspects of their rehabilitation program, such as, the design of equipment, supplies, and health care facilities. Further, because of the close ties with family members and friends and their involvement with the patients, these individuals also have a valuable contribution to make in the implementation of SCI practices. This recommendation supports the notion that if individuals have input into legislation and protocols pertaining to them they may be more committed to these acts. Inclusion of former patients in programs designed to support and teach new SCI patients was also found to be beneficial for this group of patients to "learn the ropes." This investigator suggests that establishing support groups by introducing former and current family members to each other throughout rehabilitation could provide a means for these individuals to share their thoughts and beliefs about their relative's predicament and may assist the family members to come to terms with the changes they experience as a result

of their relatives sustaining permanent damage to the spine. In this researcher's opinion, to overlook the resourcefulness of these individuals would be a grave error.

In accordance with the finding that recreational activities helped the patients kill time, promotion and support of these activities are extremely important. Given that all informants reported that leisure activities contributed to the well-being of SCI patients and their family members, continuing such programs is extremely important to the rehabilitation process of a spine injury. Opportunities for interacting with others in large groups, such as, socials, sports events, and movies provided SCI patients in this study with opportunities to interact with people in the "outside" world. The reactions of outsiders to SCI patients were important in determining the patients' acceptance into the community. The findings in this study indicate that staff's involvement, particularly the recreational therapists' coordination and organization of recreational activities served as a valuable means to integrate SCI patients back into home situations and social relationships.

Nursing care practices that are flexible enough to meet patient needs should be planned. For example, in this study, the SCI patients said that having a bath twice a week was not often enough. It is not without recognition that adequate nursing personal on all shifts were needed to assist patients with this task; however, because the patients believed this activity was extremely important to the development of their self-worth and affected their progress during rehabilitation, serious consideration to the implementation of daily baths is needed. The importance of further investigation into the allocation of washroom space pertaining to the SCI patient practices is warranted as the patients in this study felt humiliated when they had to wait in line to use these facilities. Careful planning, the construction of facilities and their use by patients cannot be overemphasized in this investigation considering patient function and their ability to maximize personal goals was influenced by the facilities that were present.

A final implication for nursing practice is the need for further research related to a spine injury. Qualitative studies that investigate, for example, the acute phase of rehabilitation, experiences with support agencies, spouses, parents, and individuals that are living in the community could have practical importance to understanding the predicament of a SCI. This research lends itself to the potential for quantitative surveys to determine the number of patients with a SCI in rehabilitation institutions, their duration of stay, and their use of equipment. Since many questions arise from each investigation, there is much work to be done in this area of study. Because nurses interact with SCI patients, their involvement in future research activities to develop a better understanding of their situations could only enhance and serve to bridge the gaps in knowledge that exists about individuals with a spine injury.

Suggestions For Future Research

In addition to the areas for further research already discussed, future research is needed to investigate the concept of "making progress," the coping mechanisms used during meal times, such as, the "flipping" of eating utensils, and the touching behaviors of SCI patients. The findings of smoking patterns, characteristics of patients that "make it," and the families involvement with their care during the rehabilitation program and once their relative is discharged from health care facilities should be tested by further research. Studies examining the physical and emotional experience of SCI patients when socializing with noninjured or other types of injured patients was lacking in the literature. Since acceptance from non-injured individuals was a significant concern for all the patients in this investigation, more work needs to be directed at understanding how SCI patients deal with everyday problems that were associated with the use of their equpiment, how they learn to come to terms with their injury, and the significance that appropriate facilities have in relation to their experience of a SCI as a whole.

Research efforts toward regeneration of central nerve system tissue, electronic stimulation, implantable devices to substitute for lost function and investigation into tissue pressure and prevention of pressure sores are areas of ongoing exploration. Clinically, there are fruitful areas for future nursing research on SCI in positioning, in prevention of pressure, in the problems which can be attributed to sensory alterations, in bowel and bladder management and in effective teaching methods for SCI patients and their relatives.

Summary

This study examined the belief systems of a SCI from the perspective of SCI patients, their friends, staff, and family members during the postacute phase of rehabilitation. There were virtually no researchers investigating a spine injury from an emic perspective. Investigators have focused on describing SCI patients' beliefs, attitudes, and concerns related to adjustment of a spine injury or identifying a variety of factors associated with emergency, acute, and the postacute phase of recovery; however, the findings in this study indicate that a variety of beliefs related to the rehabilitation process were held and that these beliefs have important influences on SCI practices. Research among SCI patients on a rehabilitation unit that includes features of their environment, a normal day, recollections, their loss, living with the equipment, their use of language and hope has been virtually non-existent. The ethnography method was used in this study to describe the belief systems of the SCI patient. Interviews with SCI patients, their friends, staff, and family members were the major source of data.

The findings that resulted from this study indicate that SCI patients hold significant beliefs related to their experience and the rehabilitation process. SCI patients' description of the rehabilitation unit, their activities, and their friends, staff, and family members concerns about the SCI predicament have been articulated. Most of the SCI patients in this study welcomed the rehabilitation program and hoped that they would

walk as they once could. Also, the patients believed that stringent work habits, health practices, proper fitting of equipment, a variety in meals, daily baths, effective communication by staff, and accessibility of a wheelchair to health care facilities were necessary to ensure progression through the rehabilitation program.

The findings in this study indicate that staff's perception of their role in managing a SCI included a working knowledge base and proper implementation of protocols and procedures, ways to influence the SCI experience to the benefit of the patients and flexibility in assigning primary nurses and related health team members. Also, the staff's perceptions of their role included measures to relieve disruptions in the patient's lifestyle, dealing with unexpected events, and collaborative and coordinated efforts to communicate with other health team members.

Parents' perceptions of the experience included additional caregiver responsibilities, role strains, adaptation to change, fear of the unknown, perceived loss, and modifications of their hope in this investigation. Most of the parents visited their relative on a regular basis on the unit, whereas, the relationships the SCI patients had with their girlfriends or boyfriends drifted apart.

New insights gained by understanding the SCI patients' perspective about their accident and factors influencing their rehabilitation could be used to guide changes in a variety of interventions aimed at supporting their personal goals. Developing appropriate interventions could enhance the SCI patient's progression to a healthy and fulfilling life. The findings in this study were consistent with other investigations in that SCI patients have belief systems that cannot be ignored by nurses or other health professionals because of their involvement in their care and that different interventions are appropriate to assist the SCI patient during rehabilitation. The findings in this study have revealed strategies patients used to cope, manage, and adapt to their injury, and these findings should be tested by further research.

The original question that guided this research was "What is the experience of being a SCI patient on a rehabilitation hospital unit?" The answers to this question have been integrated throughout this thesis and included the structural features of the SCI unit, the patients' day-to-day activities, SCI patients' thoughts and feelings about arrival and discharge from the unit, the trial and error process of learning to live with the equipment, and adult coping mechanisms, such as, the use of coarse language and the concept of hope. Anticipating living with a permanent disability created fear for the SCI patients about not "making it" in the mainstream of society. The factors influencing the patients' successful responses to coping with permanent damage to the spine were the use of the facilities on the SCI unit, getting regulated, meal times, the SCI classes, killing time, friends, staff and family members responses to them, having good and bad days, the use of coarse language, and the concept of hope.

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APPENDIX A

UNIVERSITY OF ALBERTA FACULTY OF NURSING
INFORMED CONSENT FORM FOR INFORMANTS

Project Title: An Ethnography of the Spinal Cord Injury Unit.

Investigator: Sharon Laskiwski, RN, BN,
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Home Phone: 475-4894

Supervisor: Dr. Janice Morse,
Professor
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Office Phone: 432-6250

Purpose of the Study

The purpose of this project is to observe and interview spinal cord injured patients, staff and family members so that more may be known about the culture of the spinal cord unit. Observations will be conducted on the unit and you may be invited to be interviewed. Any interview will take approximately one hour and will be tape recorded in hospital at a time that is convenient to yourself.

Consent

This is to certify that I _____ know about and agree to be a participant in this research study outlined above.

If I agree to be interviewed, I understand that I have given Ms. Laskiwski permission to talk privately with me and that any interview will be tape recorded. I realize that any names will be removed from any tape recorded interviews. I understand that the tapes and transcriptions will be retained by the researcher up to 5 years after this study has been completed. I am aware that the researcher will destroy the tape recorded interviews after 5 years of this study been completed. I agree and give my permission for the researcher to retain the transcriptions of the tape recorded interviews for an indefinite period of time and that they may be used for research and educational purposes in the future, provided the researcher seeks additional approval from the appropriate ethical review committees. It is also my understanding that while it is estimated that any interview will last approximately one hour, I am free to terminate any interview at any time. I realize that staff members will not be asked to give information about any one patient and that information about any patient will not be communicated back to any staff member by the researcher. I am aware that the researcher will report any behavior or information that is discussed by a subject that may be harmful to a patient as any researcher has an ethical obligation when conducting research activities to report such matters to, for example, the person who is in charge of the unit during the time of the occurrence. I realize that the researcher will be observing the day-to-day-activities on the unit, and that at any time I may request her to leave.

I understand that I do not have to talk about any subject I do not wish to discuss and I am assured of anonymity. Although any discussions with Ms. Laskiwski may be published, my name will not be associated with the publication. I may withdraw from the study at any time without this affecting any care I receive. There may be no direct benefits to me from any participation in this study. I have been given the opportunity to ask questions concerning the study and they have been answered to my satisfaction.

Date: _____ Signature: _____

Witness: _____ Reseacher: _____

APPENDIX B

NOTE

INFORMATION ON THIS STUDY

Project Title: An Ethnography of the Spinal Cord Injury Unit

Investigator: Sharon Laskiwski,RN,BN,
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This is an initial study for developing an understanding of the experience of being a spinal cord injured (SCI) patient in a rehabilitation hospital unit. The purpose of this study is to observe and interview day-to-day life on the spinal cord unit so that more may be known about what it is like to be recovering from a spinal cord injury. The patient's subjective knowledge and understanding of the experience will be sought.

The research question for this study is "What is the experience of being a SCI patient on a rehabilitation hospital unit?" Because this research question deals with an area where little verified information currently exists, the use of observations and unstructured interviews (that include SCI patients, staff and family members) will be used to collect the data. Any interview will take approximately one hour and will be tape recorded in hospital. All interviews will be transcribed for data analysis.

Ethical clearance for this study has been approved by the Ethics Review Committee of both the University of Alberta Faculty of Nursing and the University of Alberta Hospitals. The researcher will not have any subjects participating in this study who do not give a fully informed consent. Each subject is free to terminate any interview at any time and is not required to talk about any subject they do not wish to discuss.

The findings from this study will provide the groundwork for future research endeavours related to SCI patient's response to illness and disability and should contribute to the improvement of nursing practice.

This note is to inform you that this patient has consented to participate in this study. If you should have any further questions about your patient participating in the study, please feel free to contact Sharon at 432-8233.